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ABSTRACT

This document includes an introduction by Marie E. Cowart and the following papers: (1) "Building Partnerships" (Margaret Lynn Duggar); (2) "Rating Scale of Communication in Cognitive Decline" (Rick Bollinger and Carol J. Hardiman); (3) "Role Adaptation in the Employed Adult Female Caregiver Following Transitional Nursing Support" (Margaret H. Prackley); (4) "Support for Maintaining Independence in the Elderly--Future Requirements and Solutions: Florida's T.E.A.C.H. Demonstration Project of Home-based, Case Management Services to the Medically Dependent Elderly and their Caregivers" (Douglas D. Bradham, Innette Mary Chico, and Melody J. Marshall); (5) "Caregiving in Developing East and Southeast Asian Countries" (Nelson W. S. Chow); (6) "Economic Incentives for Family Care of the Elderly" (Jordon I. Kosberg); (7) "Caregiving Among Middle and Low Income Aged in Hong Kong" (Alex Y. H. Kwan); (8) "Potential for Abuse in Caregivers" (Alex Y. H. Kwan); (9) "The Centrality of Communication in Maintaining Independence in the Elderly" (Herbert J. Oyer, E. Jane Oyer, and William H. Haas); and (10) "Informal Care and the Use of Formal Services: Are They Related?" (Sharon L. Tennstedt). (NB)

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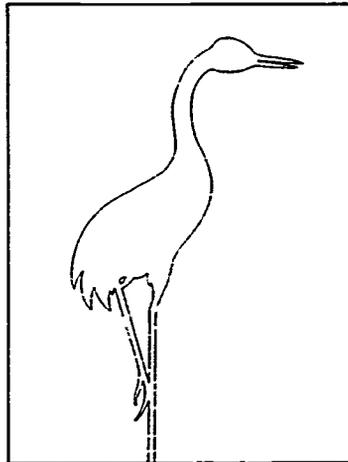
CAREGIVING: SUPPORT FOR MAINTAINING INDEPENDENCE IN THE ELDERLY

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CAREGIVING

**Support For Maintaining Independence
In The Elderly**

Florida State Conference Center
Florida State University

Tallahassee, Florida

January 27 & 28, 1987

Co-sponsors:

Multidisciplinary Center on Gerontology
Florida State University

Aging and Adult Services Program Office
Florida Department of Health and Rehabilitative Services

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INTRODUCTION

With increasing longevity, caring for parents has emerged as a major social issue in the United States, and particularly in Florida. Caregiving can be characterized as the major form of elder care that prevails today. Because it is an informal service by spouses, children, friends and neighbors, the true extent of caregiving is not known although it is estimated that 80-90 percent of elderly care is by this mechanism. Caregiving can provide benefits as well as stresses to both the care receiver and the primary caregiver. The care receiver is typically characterized as a widowed woman over 75 years old, while the primary caregiver is typified as a 35-65 year old youngest daughter who may be raising her own children and be fully employed.

In an effort to gain more knowledge about the complex issues surrounding caregiving, the Aging and Adult Services Program Office of the Florida Department of Health and Rehabilitative Services with the Multidisciplinary Center on Gerontology at Florida State University co-sponsored a two day conference on Caregiving: Support for Maintaining Independence in the Elderly at the Florida State Conference Center in Tallahassee on January 27 and 28, 1987. This proceedings is a compilation of some of the papers presented at that important meeting. The first piece is by Margaret Lynn Duggar, Director of the Aging and Adult Program Office, who's concern for the unknown stresses endured by caregivers was the impetus for this conference. Her presentation gives direction and hope for addressing Florida's caregiver issues. Other presentations provide research findings of studies about caregiving interventions that will be helpful to members of the aging network who deal with caregiver issues in the field. An international perspective helps us to understand that caregiver concerns are universal and must be dealt with through careful blending of formal services and social policy to support the informal system of care.

This volume was made possible through funding from the Aging and Adult Services Program Office of the Department of Health and Rehabilitative Services and the Multidisciplinary Center on Gerontology at Florida State University. Special appreciation is extended to Barbara Hines who typed and formatted the manuscripts.

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June 30, 1987

Caregiving: Support for Maintaining Independence in the Elderly

Table of Contents

Introduction Marie E. Cowart	ii
Building Partnerships Margaret Lynn Duggar	1
Rating Scale of Communication in Cognitive Decline Rick Bollinger and Carol J. Hardiman	09
Role Adoption in the Employed Adult Female Caregiver Following Transitional Nursing Support Margaret H. Brackley	15
Support for Maintaining Independence in the Elderly-Future Requirements and Solutions: Florida's T.E.A.C.H. Demonstration, Project of Homebased, Case Management Services to the Medically Dependent Elderly and their Caregivers Douglas D. Bradham with Innette Mary Chico and Melody J. Marshall	19
Caregiving in Developing East and Southeast Asian Countries Nelson W.S. Chow	35
Economic Incentives for Family Care of the Elderly Jordon I. Kosberg	44
Caregiving Among Middle and Low Income Aged in Hong Kong Alex Y.H. Kwan	53
Potential for Abuse in Caregivers Alex Y.H. Kwan	61
The Centrality of Communication in Maintaining Independence in the Elderly Herbert J. Oyer, E. Jane Oyer, and William H. Haas	67
Informal Care and the Use of Formal Services: Are They Related? Sharon L. Tennstedt	75

BUILDING PARTNERSHIPS

Margaret Lynn Duggar, Director
Aging and Adult Services Program Office
Department of Health and Rehabilitative
Services

Did you know that there are more than a million partnerships in Florida's Aging Network?

A conservative estimate drawn from only seven of our aging programs in Florida reveals a minimum of a million partnerships.

You may know that our Older Americans Act program, for instance, is serving over 200,000 different people and this year will probably touch the lives of over 300,000 different people through seven community programs, including the Community Care for the Elderly Program, Home Care for the Elderly Program, Adult Congregate Living Facilities, Adult Foster Homes, Adult Day Care, and our unique, special, and dynamic Alzheimers's initiative.

It's amazing indeed! Over a million partnerships in Florida's aging network, and many of them are with and for caregivers.

Let us direct our attention to the word "Caregiver." Interestingly, no such word exists in the dictionary. We can find the words, care and giver, which mean:

Care, a burdensome sense of responsibility, anxiety; and, Giver, one that gives, a donor.

Together, we can concoct a definition for the word caregiver. As one who prefers a positive approach to the role of caregiver, the terms "burdensome" and "anxiety" are inappropriate. A caregiver can more accurately be described as a person who accepts the responsibility of providing care, and gives his or her time and energy to meet the needs of another person.

Building Partnerships with caregivers involves the participation of those who join in providing a continuum of care by giving their time and energy for others.

We can ease the responsibility of caregiving by creating true partnerships between health and social service professionals as well as family, friends, and neighbors (Brody, 1985). Whether nurse, physician, physical therapist, dietitian or social worker, the collective goal is to support the management of care in the least restrictive setting, regardless of whether the client might temporarily be in an acute care hospital, a nursing home, an adult day health center, or their own home. Such partnerships form the basis for the continuum of long-term care.

To do this effectively, we must build partnerships which recognize the options available to our loved ones. We must be knowledgeable of what each party brings to the role of caregiving. The lines of communication must be open between participants. We, as professionals, must understand that before us and after us most of the care the elderly person receives will continue to be from their relatives, friends and neighbors. We must act to assure that the best care possible is made available through joint efforts, and that holistic care is available for all of our clients. This can and will be done

by building true and abiding partnerships.

Building partnerships, as we have at the Florida State University Multidisciplinary Center on Gerontology, and through our international partnership between Hong Kong and the United States there are good examples of sharing special skills and information.

Florida's Aging Network is also a partnership of local, state, national, international, non-profit and proprietary agencies dedicated to provide services to the frail elderly in a state whose population will grow by the year 2000 to 14.7 million, making us the fourth most populous state in the United States. Latest demographics for Florida (Florida Concensus Estimating Conference, July, 1986):

1987	1990
60+: 2.9 million	60+: 3.2 million
65+: 2.2 million	65+: 2.5 million
75+: 920,000	75+: 1,055,000
85+: 180,600	85+: 216,304

We are finding through updates of our demographics, that previous projections for the year 2000 will be reached by 1990.

The elderly population is getting older, has a growing number of veterans, a majority are females, many are living alone without extended family nearby to call upon if needed; and, many will have multiple service requirements. This is the population which challenges us to build partnerships with the families and friends who provide direct care for our elders and who have long been a most important ingredient in Florida's community care programs.

According to Dr. Elaine Brody (1985), a nationally recognized expert with the Philadelphia Geriatric Center, families today provide for at least 80 percent of the care required by America's elderly population. Elderly wives, husbands and friends most often fill the caregiver role, and it is this group of committed individuals that Florida's community programs seek to assist their daily duties.

I'd like to highlight several of Florida's unique community programs that provide home-based support to frail older persons and their caregivers.

The first community-based program is Home Care for the Elderly which will serve over 9,000 Floridians this year. The program recognizes the importance of preserving strong partnerships through two important objectives: First, a small cash stipend, averaging \$816 per year, provides a subsidy to families as an incentive to keep their elderly family member at home rather than in nursing homes. Each family caregiver has a contract agreement with the State's program and submits a voucher for direct payment every month. Due to this direct care arrangement, the income received as a cash subsidy is counted as basic subsistence rather than as income to the caregiver or the client. It is a Dynamic Partnership! Secondly, the periodic case manager contact helps to remove the fear and confusion of utilizing the private care system by providing professional advice and support.

It is interesting to note that Florida's Home Care for the Elderly program received no administrative funding or staffing increases during its first five years of operation. Currently, we do have staff dedicated to Home Care for the Elderly clients and their caregivers.

Partnerships are also being developed through programs for Community Care for the Elderly or Older Americans Act funding, as well as by writing grants and proposals to foundations, charging fees for service, developing voluntary community self-help programs, working with private business to obtain cash or in-kind support, linking clients with existing formal services and developing informal networks on behalf of clients by involving family and neighbors as caregivers (Mahoney, 1987). One quickly realizes that many simultaneous efforts must occur in order to develop and maintain successful partnerships.

We must also recognize that public funding does not appear to be the answer for the future. The brightest minds in the country are wrestling with alternatives for financing long-term care services. No clear answers have been found. We do know that deficit reduction will continue under Gramm-Rudman, and other programs, similar to Home Care for the Elderly, must be explored and tested. We cannot and dare not wait for solutions to simply emerge. We must be innovative and act with the resources at hand. We must build partnerships that apply the full range of knowledge, ability and funding to effectively meet the needs of the frail elderly population.

Another of our very dynamic model initiatives is Florida's Community Care for the Elderly program (CCE). Our CCE program is administered by the State Aging and Adult Services Program Office through contracts with the district offices and the Area Agencies on Aging (AAAs). The 67 CCE Lead Agencies cover all counties in the state. Care services are designed to provide support and assistance with any activity of daily living which a client cannot perform independently. There are 14 services in this program.

Building partnerships is one of the most important activities of the Aging Network and many new partnerships are being formed through the seven Community Service System (CSS) demonstration projects being funded throughout the state. This CSS system has forged many new partnerships between the state, local, and private sectors. Visualize with me this system of our future:

- o Case management will occur across all program lines.
- o Coordination of information and services will be provided through common case management.
- o An active and supportive coalition of aging services providers (public/private, private/nonprofit/profit, and local neighborhood organizations) will be built.
- o Outreach to communities at risk will be provided through mobile service units, and client advocacy teams.
- o Coalition-wide computerized client information systems will be available.
- o Coordination of resources will assure their most effective utilization (Pathways III, 1986).

The essence of the CSS program is that partnerships among the coalition of aging services must be built, with or without funding. The Community Service System will continue to be a major focus of our effort in the future as we develop coordinated service delivery models in every community. It is for this reason that case management must direct its focus on a broad array of resource development issues, emphasizing a client-

centered orientation, with access to the widest range of services offered by formal and informal networks.

Many studies show that the provision of formal services can improve caregivers' satisfaction with life and will not necessarily reduce the amount of informal caregiving (Christianson, 1986).

Our 1986 CCE evaluation included this area as one of the components of research. We found that the stress level of caregivers, whose elderly relative had been receiving services for a year, was lower than the stress level of caregivers whose elderly relative had been assessed for services but for whom services had not yet begun. We have clearly demonstrated in a small way that our CCE services can reduce the stress of caregiving. Health care and social services in the comfort and security of their home give an older person and his or her family and friends a sense of independence, control and peace of mind. Home services also help to reduce the strain of expensive hospital or nursing home stays during a long-term illness or disability. Remaining at home also helps many older persons maintain social ties and involvement with their community, neighborhood, friends and family, and preserves their sense of independence and security. However, the caregiver needs respite, a very important period of time to be alone, collect one's thoughts and become centered again.

Anne Morrow Lindberg (1955), describes this time as listening to the "Inner Music."

She says, "It's a difficult lesson to learn today - To leave one's friends and family and deliberately practice the art of solitude for an hour or a day or a week. For me, the break is the most difficult. Parting is inevitably painful, even for a short time. It is like an amputation, I feel. A limb is being torn off, without which I shall be unable to function. And yet, once it is done, I find there is a quality to being alone that is incredibly precious, life rushes back into the void, richer, more vivid, fuller than before. It is as if in parting one did actually lose an arm. And then, like the star-fish, one grows it anew; one is whole again, complete and round - more whole, even, than before when other people had pieces of one." (Lindberg, P.42, 1955)

It is this renewed, whole-again person who is the most effective caregiver. "Inner music", a partnership with health and respite care and other support services, is a very unique and special partnership.

We have, thus far, focused on the dependency issues related to caregiving, the need for services, the provision of services to fill those needs, and the stresses that occur. I am compelled to present a more balanced view. There are numerous joys of caregiving. The joys of caregiving are most obviously manifested in the gift of self that the caregiver offers to the loved one. There are also many special, warm, touching, funny times together which are meaningful to both the recipient of care and the caregiver. While the more positive aspects of caregiving do not lessen the need of services nor the stresses of caregiving, it is appropriate for us to understand the bonding that often occurs between the caregiver and frail older person, and the communication and intimacy that frequently results from the changing relationship between caregivers and the frail older person. As leaders in the field of aging, we must include in our views about caregiving the joys as well as the frustrations, the rewards as well as the sacrifices.

We must constantly remind ourselves that the needs caregivers meet and the needs caregivers have are really relatively basic. I worry sometimes, that as we organize, structure and categorize needs, we lose their basic meaning. I worry that we aggregate needs until they lose their significance. I want to ensure that, as we develop techniques such as case management, we do not forget that the most significant need is for communication -- someone to listen, someone to be supportive, someone to respond. When we aggregate basic activities like bathing and dressing, under the heading of personal care, let us not lose sight of how essential these activities are to each of us every day -- and how frustrating it would be not to have those services performed for us or our loved one as often as they are needed. Let us not be distanced from these needs. We must maintain our sensitivity to their importance.

Another critical area that we must begin to address is the ethical aspects of the caregiving relationship.

The issues are varied and exceedingly complex. Not only are there no easy answers -- there are no answers! But, this issue may be the most significant one for decision makers in the future. Embodied in the question are the issues of distributive justice. What resources will be available and how will they be allocated. One example of the distributive justice challenge today relates to the institutional bias of Medicare and Medicaid in their funding of health care services. Less than three percent of Medicaid funding and less than one percent of Medicare funding goes to in-home community services. The issue of community-based alternatives is tremendously impacted by the federal policy decision to fund institutional care.

Also embodied in the question of ethics is the challenging issue of the value that our society places upon people who work, who produce goods and services and who get paid to do so, versus those individuals who are unable to work, or who choose not to work. We value work and productivity, but our society de-values dependent persons, non-working persons and non-productive persons. We are concerned about the image of self-worth of frail older persons in relation to this productivity value. Further, we are concerned that our society value, and not de-value, the important contributions being made by caregivers. We were particularly encouraged by an article in Productive Aging News - Mt. Sinai:

"All in the Family: Productivity We Ordinarily Don't Measure". The productive behavior of older people in terms of serving the chronically ill -- particularly in helping them live outside of institutions -- was recently documented by the National Center for Health Services Research. The study showed that nearly 2.2 million caregivers, mostly "young-old" wives and daughters, are caring for nearly 1.2 million elderly persons in their homes with little or no outside help. Only 10 percent of all caregivers use some formal (paid for) services in caring for their disabled elderly.

Younger caregivers often face conflicts between family and job responsibilities. Some have to quit their jobs to care for their disabled relatives. Among the one million caregivers who do hold jobs, 20 percent work fewer hours, 20 percent take time off for caregiving, and a third rearrange their schedules. There is also a competing need to care for children among the quarter of the daughters and a third of daughters-in-law, sisters and other female caregivers. These obligations often last from one to five years, causing much conflict and lifestyle change for the caregivers" (Stone, Cafferata and Sangl, 1986).

While these are critical ethical issues, they are not my most important challenge to you today. Our major ethical concern rests with the issue of autonomy in decision making by older adults, particularly the autonomy in decision making by frail, dependent older adults. Frail adults must be involved in the decision making about all aspects of their life and of their health care, social services, case management, homemaker services, personal care, meals and all aspects. I worry that our case managers, in very unintentional, subtle ways, make service delivery decisions for clients. I worry that our homemakers, personal care workers, home health aides and other in-home workers, unintentionally, create further dependency in frail persons by doing for them those things they could do for themselves. I fear that families make decisions about living arrangements and financial transactions for older adults instead of with them. I am concerned that physical dependency, physical frailty is often equated with the inability to know what is best for oneself and to know what one wants for oneself, which may not be one and the same thing!

Certainly, at other ages and other stages in our lives, we make very conscious decisions about knowing what is best for us and what we want, and we should be able to make these decisions on into our advancing years even if physical frailty intervenes.

We are creating dialogues in many arenas about the ethical aspects of aging policy. The Florida Committee on Aging spent an intense weekend in December 1986, discussing the issue. Soon, we will conduct a one-day "Ethical Issues in Aging" Conference for Florida Legislators, and a dynamic Ethics and Aging Conference will be held in Miami. We are moving these discussions forward on a statewide basis as you must at the community level. We will be glad to assist you, but you must initiate these discussions among staff, boards of directors, and policy makers among your community leaders and caregivers.

It has been made extremely clear during the past two days that caregiving is a very significant phenomenon in the field of aging today and will continue to be in the future. The good news is that the advances we are making seem to be for the better.

In response to our demographic challenge, we are building new partnerships, while at the same time demand for our services is increasing dramatically. To meet this demand we must focus our attention on new approaches, such as:

- o Partnerships between Aging and Adult Services and Area Agencies on Aging in establishing a family caregiver hotline and an accessible statewide data bank to provide information on formal and informal resources (educational, service, and economic) that are available to family caregivers.
- o Another new approach would be for local agencies to explore assisting churches, synagogues and other organizations to develop caregiver outreach projects.
- o Case managers should be trained in developing public and private partnerships on behalf of their clients.
- o CCE core services should be expanded and available in all areas of the state.

- o Innovative forms of incentive policies should be stimulated through the development of public/private partnerships and the development and allocation of resources to support demonstration projects to test the relative effectiveness of various models (Biegel, 1986).

It is imperative that our views of the future be solidly based on an understanding of the effects of our current practices and their suitability in addressing the issues that a rapidly changing society presents. No single state is more important to study demographically at this juncture than the State of Florida.

To recap, the last two days have afforded me - you - us - all - TOGETHER - the opportunity to communicate, to learn, and to Build Partnerships. The future, we design together -- the present, we control together. Let us commit to continue to build caring, innovative, effective Partnerships for Tomorrow. Thank you.

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RATING SCALE OF COMMUNICATION IN COGNITIVE DECLINE

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With the increased awareness and attention to the Alzheimer's condition, it has been apparent that amelioration, arrest, and immunization are not possible. In dealing with the unrelenting progression of the disease, the caregiver faces a variety of behavioral difficulties. The influence of orientation, memory, and generalized cognitive-intellectual deterioration are well documented and apparent to all those who have academic or situational involvement with the Alzheimer's patient. It is not surprising that caregivers, regardless of life's station (family, paid homecare companion sitters, or staff in long-term care facilities) are confronted with miscommunication, communication breakdowns and lack of communication between them and the Alzheimer's patient.

Among demented persons, there are three internal, primary factors that influence the success of communicative interaction. These are memory, reasoning-judgement (discussed here as cognition), and language. The memory-cognitive decline in dementia is in and of itself sufficient to effect breakdowns in communication. Attentional deficits may create a poor awareness of the onset of a message, short term memory deficits may result in an inability to gain meaning from a message and long term memory deficits may result in difficulties retaining and relating early and later language units for appropriate meaning to be derived. The general cognitive decline with its inherent decrements in reasoning and judgement result in error interpretation of a message. During the early stages of cognitive decline, language can be used to augment these diminishing memory and reasoning abilities. As the disease progresses, however, language per se becomes involved and the caregiver must rely on the other communication strategies.

The generalized cognitive-communicative disorder characteristic in dementia is additionally compromised by changes in the language system. Some writers argue that aphasia, a specific neurogenic language disorder, is present among all Alzheimer's individuals. Others suggest that a specific language disorder (aphasia) may be present in only some individuals, though all will present anomia, a behavior most commonly associated with dementia. Regardless of the inclusiveness of the occurrence of aphasia, it is generally accepted that Alzheimer's individuals present some degree of cognitive-linguistic disorder, that, when occurring within a framework of generalized intellectual impairment, results in a significant communication impairment.

Mace in her chapter on "Self-Help for the Family" (1984) notes that communication difficulties are within the top six of twenty behavioral problems most commonly reported by the family caregiver(s) of Alzheimer's patients. Indeed, this breakdown in communication contributes to the depression, fatigue, anger, family conflict, and loss of friends that are reported by these caregivers.

Resources that enable families and caregivers to continue to cope with and successfully care for an ill relative over a prolonged period include information and symptom management skills. The Rating Scale of Communication

Decline (1986) developed by Bollinger and Hardiman was devised as such a resource for the caregiver. Through its use, the caregiver has a guide for determining the general level of communication of a demented person and is able to establish a foundation for the development of sensible communication strategies. The caregiver rates the demented person's communicative abilities in the areas of verbal and nonverbal communication according to the availability of language as a communicative tool.

A scaling of the patient's communication abilities is completed by the caregiver during observation of abilities in situations where routine communication interactions are expected to occur. For example, rating may be completed during socialization in a day room, during family visits or during meal time. Ideally, when possible multiple observations and ratings should be done at different times of the day and in different situations over a week's time to get an idea of variability of performance over time.

The rating scale includes 20 items and has two sections, Verbal and Nonverbal. Each item is rated on a five point scale that designates the frequency of occurrence of a given communicative behavior. Scores are assigned as follows: behavior is present, rated 5, (scored 1.0); mildly disordered, rated 4, (scored 0.75); moderately disordered, rated 3, (scored 0.50); severely disordered, rated 2, (scored 0.25); absent, rated 1, (scored 0.0). Ten verbal and ten nonverbal items are included.

The Verbal section includes items that describe pragmatic categories of speech and language. These items address the primary communication modalities with emphasis upon verbal output and auditory input. The Nonverbal section has items designed to provide information regarding the availability of low level cognitive capabilities that have direct influence upon communication. It is divided into two subsections, self-awareness and environmental awareness. Like the Verbal items, the Nonverbal items are rated according to the 5 point scale, but receive only half the weight in scoring. The weighting has been devised to emphasize the functionally more expeditious verbal skills.

Once the rating is completed, points are subtalled in Verbal and Nonverbal areas, totalled, and a verbal/nonverbal ratio is obtained. The Total Score is used to yield a level of communicative-cognitive abilities which is then used to apply various communication strategies as suggested by Bollinger and Hardiman (1986) on an accompanying scale entitled Strategies for Communication Management in Cognitive Decline. The verbal/nonverbal scores are totalled and the ratio derived allows the caregiver to determine how much attention should be given to the verbal or nonverbal areas. Most people, however, depend on the Total Score to give them a marker where the patient is functioning at that point in time.

As an example, Kathleen is a 74 year old female diagnosed as Alzheimer's who lives at home with her husband. On the scale, Kathleen's verbal performance is high, showing deficits only in word choice, while she does evidence the ability to request assistance in recall. Overall, nonverbal performance is also relatively intact though she shows some loss of awareness of other's emotional responses and she fluctuates in her awareness of physical environmental changes. Her total rating comes out to be 14.40 placing her at Level 9 (Early Stage) on the Strategies for Communication Management in Cognitive Decline, Bollinger and Hardiman, (1986). This tells the caregiver that verbal message is primary and no major adjustments are needed in the sender or demented person's communication. The only area of deficit noted is in forgetting names of familiar persons and strategy is suggested to the caregiver to assist in dealing with this problem. Table 1 provides an example of Kathleen's scaled performance.

(See Table 1)

The second example is Terry, a 68 year old male diagnosed as Alzheimer's who resides at a VA Long Term Care facility. Terry's performance is rated as severely involved in the verbal area, with somewhat less involvement in nonverbal abilities. His verbal/nonverbal ratio shows strength in the nonverbal area with a total rating of 4.60. This performance places him at Level 3 (Late Stage) which indicates that he has significant difficulty attending to verbal stimuli and expressing his ideas through words and sentences. It was noted that he attempted to use repetitive speech events or motor movements to maintain some measure of control in a communication situation. Because of his level of involvement, physical manipulation is necessary to gain his attention. Exaggerated facial expression and intonation of speech is necessary. Attention should be shown to maintenance of eye contact, use of short relevant input and much repetition. Observation of behavior to communication event is necessary by the caregiver. A sample of Terry's rating scale is presented on Table 2.

(See Table 2)

The training of caregivers in the use of the Rating Scale of Communication in Cognitive Decline, Bollinger and Hardiman, (1986) enables a practical assessment of functional communication abilities and the application of an optimal communication approach through use of the accompanying strategies. The scaling of communication behaviors and implementation of enhanced communication techniques should enable caregivers to develop more appropriate expectations with resulting improved communication success. Such designated strategies will encourage demented persons functioning at a level that more nearly matches their cognitive-communicative abilities.

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TABLE 1

RATING SCALE OF COMMUNICATION IN COGNITIVE DECLINE

Rick Bollinger, Ph.D. and Carole J. Hardiman, M.S.
Miami Veterans Administration Medical Center and
The Florida State University

Name: Kathleen
Date: 8-8-86
Rater: CJH

Present = 5
Disordered: Mild = 4, Moderate = 3, Severe = 2, Absent = 1

VERBAL

	5	4	3	2	1
1. Expresses ideas, feelings, thoughts. (<u>1.0</u>)	.75	.50	.25	0	
2. Expresses physical-emotional needs. (<u>1.0</u>)	.75	.50	.25	0	
3. Corrects any errors of word choice. 1.0 (<u>.75</u>)	.50	.25	0		
4. When forgets, requests assistance in recall of a name or word. 1.0 (<u>.75</u>)	.50	.25	0		

NONVERBAL

Self

1. Indicates physical needs in some way (<u>.50</u>)	.45	.25	.15	0	
2. Demonstrates appropriate emotional response. (<u>.50</u>)	.45	.25	.15	0	

Environment

3. Demonstrates awareness of physical changes in environment. .50 (<u>.45</u>)	.25	.15	0		
4. Evidences awareness of people who come into his/her environment. (<u>.50</u>)	.45	.25	.15	0	

Total of Rating (V + NV Subtotals): 14.40 - Level 9

Verbal-Nonverbal Ratio (V Subtotal / NV Subtotal): 9.50/4.90

Stage: Early

TABLE 2

RATING SCALE OF COMMUNICATION IN COGNITIVE DECLINE

Rick Bollinger, Ph.D. and Carole J. Hardiman, M.S.
Miami Veterans Administration Medical Center and
The Florida State University

Name: Terry
Date: 10-8-86
Rater: CJH

Present = 5
Disordered: Mild = 4, Moderate = 3, Severe = 2, Absent = 1

VERBAL

	5	4	3	2	1
1. Expresses ideas, feelings, thoughts.	1.0	.75	.50	(.25)	0
2. Expresses physical-emotional needs.	1.0	.75	(.50)	.25	0
3. Corrects any errors of word choice.	1.0	.75	.50	.25	(0)
4. When forgets, requests assistance in recall of a name or word.	1.0	.75	.50	.25	(0)

NONVERBAL

Self

1. Indicates physical needs in some way	.50	.45	(.25)	.15	0
2. Demonstrates appropriate emotional response.	.50	(.45)	.25	.15	0

Environment

3. Demonstrates awareness of physical changes in environment.	.50	.45	(.25)	.15	0
4. Evidences awareness of people who come into his/her environment.	.50	(.45)	.25	.15	0

Total of Rating (V + NV Subtotals): 4.60 - Level 3

Verbal-Nonverbal Ratio (V Subtotal / NV Subtotal): 1.75/2.85

Stage: Late

**ROLE ADAPTATION IN THE EMPLOYED ADULT FEMALE CAREGIVER
FOLLOWING TRANSITIONAL NURSING SUPPORT**

**Margaret H. Brackley, Ph.D., A.R.N.P.
Assistant Professor of Nursing
Florida State University**

Parent care by adult daughters is the most prevalent type of care for the elderly when a spouse is unavailable or unable to assume the role (Stroller, 1983). The caregiver is typically in the middle generation, in her middle years, and has a multiplicity of role demands (Brody, 1981). Caregiving, while time consuming and potentially stressful, is a role readily assumed by most adult daughters as part of their filial responsibility. Affection is not a necessary prerequisite to parent care (Jarrett, 1985). The satisfactory development of the caregiving relationship depends on many variables. Among these variables are the post parent-child relationship, the daughter's present situation, the parent's health, and available family supports. Role redefinition and renegotiation are a necessary part of the transition to caregiver (Fischer, 1981).

No socialization processes exist that dictate an orderly transition to the caregiver-care recipient roles. Successful adaptation to these complimentary roles has not been defined (Johnson and Catalano, 1983); no normative data exist that describes successful adaptation. Caregiving has been identified as burdensome in some respects. Subjective and objective negative effects, while complex and undefined, have been described in the literature (Poulshock and Deimling, 1984). These effects on caregivers are physical, financial, emotional, social, and mental (Archbold, 1982). Role insufficiency, the perception that one is inadequate for an anticipated new role, has been identified as one way to review these effects (Brackley, 1986).

The transition from the role of adult daughter to that of parental caregiver is an example of a stressful situation when a client might need support from a professional nurse. An intervention that has been used over the last decade by many types of professionals to provide support to family caregivers has been support groups. Meleis (1975) suggested a type of educational/support group, she labeled a role supplementation group, as an intervention that nurses could use for prevention or treatment of role insufficiency. Role supplementation was defined by Meleis as: a deliberate process whereby information or experience is conveyed in an effort to increase the awareness of anticipated behavior patterns, sentiments, sensations, and goals involved in each role. Meleis proposed the use of peer groups as an important strategy of role supplementation during role transition. The transition from adult daughter to parental caregiver is an example of this type of transition. The author also called for descriptive research to identify behavioral manifestations of role insufficiency. She pointed out that these manifestations associated with role transitions may be characterized by anger, hostility, withdrawal, confusion, depression, fatigue and anxiety.

Clark and Rakowski (1983) reviewed literature related to the use of groups in helping families cope with the demands of caregiving. Eleven reports of interventions that used support groups for caregivers were reviewed by the authors; seven of those groups cited were designed for relatives of noninstitutionalized elderly and were conducted between the years of 1979 through 1982. None of these group offerings had the benefits of a control group; one had pre/post questionnaires of the group's effects.

Presently support groups are being used in the clinical setting without benefit of empirical evidence of their effectiveness (Steuer, 1984).

Social support has been suggested as a necessary requisite to healthy caregiving. In the past, nurses have used interventions designed to improve social support both directly and through manipulation of the individual's social network. A role supplementation group has been defined as a support strategy to affect a daughter's transition to caregiver.

In this study the hypotheses under investigation were:

- 1). The adult child who exhibits high levels of social support and who receives role supplementation as a form of nursing support will demonstrate less perceived role insufficiency;
- 2). The adult child who exhibits high levels of social support and who receives role supplementation as a form of nursing support will demonstrate higher levels of role adaptation.

The ultimate purpose was to determine the effectiveness of a role supplementation group for facilitating role adaptation and preventing role insufficiency in midlife women faced with care for their elderly parents.

METHODOLOGY

A systematic sample of women who were employed at a state health sciences center was selected from the directory of faculty and staff of that institution. The criteria for inclusion in the study was: the subject must be 30 years or older, English-speaking, female and live separately from her mother. The daughter had to agree to attend 4 role supplementation sessions if assigned to the experimental group, and her mother had to agree to complete one questionnaire mailed to her residence. The 30 daughter subjects who met the criteria and agreed to participate in the study were randomly assigned to experimental and control groups; 22 subjects completed the data collection process. After baseline data collection was completed, ten women assigned to the experimental group attended the role supplementation group. At the completion of the group experience, all subjects completed the posttest data. No support was discovered for Hypothesis 1 which predicted a decrease in role insufficiency for those subjects who received role supplementation. Support was found for Hypothesis 2 which specified increased levels of role adaptation for women who received role supplementation. These findings are discussed below.

DISCUSSION

Women who exhibited high levels of social support and who received role supplementation did not have significantly decreased levels of perceived role insufficiency as predicted by Hypothesis 1 in this study. This finding was not unexpected. Even though Steuer (1984) warned of the potential negative effects of raising awareness of the caregiver's plight through educational and support groups, harmful effects of group interventions with caregivers have not been reported in the literature. Steuer (1984) wrote that denial is the primary defense mechanism caregivers use to meet uncomfortable role demands. When they develop insight into their present situation depression and other harmful effects might occur. Hypothesis 1 of this study was a test of this supposition. Although no significant decrease in role insufficiency was found in the subjects, it should be noted that no significant increase occurred either.

When the effects of social support were removed from the dependent variable role adaptation, the subjects that received role supplementation had higher levels of role adaptation than those subjects who received no role supplementation. Support for Hypothesis 2 was an expected finding both from a theoretical perspective (Meleis, 1975) and from a review of published literature (Pierskalla & Heald, 1982). Meleis (1975) wrote that role supplementation during periods of role transition was one form of nursing support available to nurses in assisting clients with role adaptation. This strategy appears to be effective for the suggested purpose.

IMPLICATIONS

From a theoretical perspective, the relationship of transition support to role adaptation during role transition was demonstrated. This finding supports the notion that role transition can be anticipated and that transition support can be effective in role adaptation. Furthermore, specific supportive actions of the nurse were identified as those of role supplementation group leader. The fact that increasing awareness through role supplementation did not increase role insufficiency seems relevant, but due to the small sample size further testing with larger samples is necessary before conclusions can be drawn.

With regard to nursing practice, several implications have relevance in the areas of program development and implementation and advocacy. Nurses practicing among the elderly should be aware of their family support systems. These family supporters should be offered support services aimed at decreasing the stresses attached to the caregiving situation. The following recommendations are made for nursing practice:

- 1). The influence of family support on the care of elderly persons should be included in the curricula of nursing schools.
- 2). Role supplementation groups for families involved in parent care can be implemented by professional nurses. The need for supportive family care will probably increase as the population of persons over 75 years of age increases in the 1990's.

RECOMMENDATIONS

Some of the recommendations that have evolved from the current investigation are:

- 1). Replicate this study using a larger sample.
- 2). Develop and test an instrument which more closely measures role adaptation in the role of the caregiver and the counterrole of the care recipient.
- 3). Develop and test an instrument that predicts role transition awareness in both role partners. Such an instrument should aid in definition of the critical times for nursing interventions aimed at role supplementation.

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**SUPPORT FOR MAINTAINING INDEPENDENCE IN THE
ELDERLY - FUTURE REQUIREMENTS AND SOLUTIONS:**

**Florida's TEACH Demonstration Project -
Home-based, Case Management Services to the
Medically Dependent Elderly and their Caregivers -
What We Hope to Learn**

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ABSTRACT

The VA in Florida (District 12) and the Florida Department of Health and Rehabilitative Services (HRS) are planning a unique cooperative demonstration for medically dependent elderly and their caregivers under Medicaid waiver. HRS desires to demonstrate the effectiveness of nurse case-managed home services in conjunction with caregiver training. The VA perceives a need to deliver medical case-management services to veterans who currently do not receive home-based services due to the geographic restrictions of the VA's Hospital-Based Home Care Program (HBHC). Consequently, an opportunity exists to develop coordination agreements of cost sharing between the VA and HRS that result in local service delivery to the elderly. The demonstration includes an independent evaluation.

The evaluation project has two major phases (1) service evaluation and (2) interagency coordination evaluation. The service evaluation will assess three outcomes: service cost-effectiveness, impacts on the care receiver and caregiver, and impacts on health service utilization by the targeted Medicaid population over 65. The inter-agency coordination evaluation will describe the coordination efforts in terms of: domain consensus, goal congruence, and communication. This paper discusses the TEACH Demonstration Project, its conceptualization, development and implementation within the context of caregivers' problems today, and the future. The Evaluation will provide insights to the caregivers' burdens and potential solutions.

INTRODUCTION

The theme of this Conference is the caregiver. Over the past two days we have learned who they are, things that should be considered in designing new programs, and ideas from across the state, the country and abroad. This morning our task is to think about what future requirements will be and what solutions might be suggested.

It was our hope that my coauthors, Innette Chico and Melody Marshall, and I would be able to show you the very early returns from a unique demonstration project for a new service to Florida's elderly and their caregivers. Contract delays have put service delivery behind schedule, so we have no data yet. The good news is that we expect services to begin next month. For those of us who have nurtured this project from its infancy, we are quite pleased to see this progress, and we have grown accustomed to the delays involved in such a complex service demonstration. Given that complexity, it is a credit to three key persons in HRS Aging and Adult Services who have maintained the necessary support and energy since early 1984 to achieve this goal. Margaret Lynn Duggar, June Noel, and Dawn Pollock, the TEACH State Coordinator, deserve our thanks for seeing that this concept became a reality.

In this paper, we will describe what we see as the future caregiver's problems and how the TEACH Evaluation effort will offer some guidance to possible solutions of some of those challenges.

We must see these problems as challenges, some with easier answers than others. It is a fact that we can solve many logistical and technical problems. But still, there remain some fundamental human challenges that may never be solved. These challenges, like the degenerative conditions that are associated with aging, can be significantly ameliorated by creative responses. As evidence, we have seen dramatic increases in life spans over the past fifty years by solving technical problems. Increased longevity and its associated chronicity in concert with other trends have precipitated the elderly's burgeoning demographic imperative -- an imperative that demands humane services at low cost to the recipient and to society.

Elaine Brody has suggested that caring for the elderly has become "a normative experience". We do not disagree, but see this issue through a different disciplinary screen. The public policy issues at all governmental levels appear to distill to "who gets what, when, and how, at what cost and who pays?". Many policy makers know the elderly's plight well. They have parents of their own. They also have several Hobson's choices to make daily; and the drive for cost-containment is quite strong with society's competing needs and limited public and private resources. This situation demands that resource scarcity must be considered constantly while seeking to meet the challenge posed by the demographic imperative. So, it would seem that the normative experience of caring for our elderly is a "normative economic one", and we therefore need to find innovative solutions to the challenges that spread the financial burden across the family, the public, industry, and the elderly.

Some believe that nothing new can be proposed - that only variations on old approaches can be offered. Regardless, it is through creative demonstration projects like TEACH that new responses can be evaluated and the best solutions turned into realities. One important role for the service industries and government is to cooperatively fund and implement these demonstrations. The point is, we have little time in some states, like Florida, to meet the challenge.

This discussion will not review the litany of elderly demographics or descriptive data concerning caregivers and their challenges. We will describe the TEACH service delivery model in some detail; issues for the caregiver now and in the future, and the planned TEACH Evaluation Project.

Introduction to the TEACH Demonstration and its Evaluation

Both the Florida Aging and Adult Services Program within HRS and District 12 of the Veterans Administration are engaged in the TEACH demonstration. Obviously, these two agencies have recognized the value of caregivers, and the potential for improved quality of life if the medically dependent elderly are kept at home. The potential public savings to be gained from avoided or delayed nursing home entry has not been lost on the policy makers in these agencies either.

The project has been called "T.E.A.C.H." because it will Train the Elderly And their Caregivers at Home. The primary goals of the TEACH Demonstration are: (a) to reduce Medicaid nursing home expenditures by delaying or avoiding nursing home placement and (b) to provide improved support for informal care by the family and other caregivers. TEACH services can be described as home-based, nurse case-managed service to medically dependent elderly in conjunction with training and support of their informal caregivers by the visiting nurse. That is the key innovation in the delivery concept - the health provider also supports and monitors the caregivers; trains them for their health support tasks; and supports their process of dealing with the various burdens from stress, long hours, physical deterioration and others. Another unique aspect of the project is the cooperative approach between the VA and the state-wide HRS organizations. The Evaluation Project will address both the health impact and the cost-effectiveness of the new service for Medicaid clients, and the process of inter-agency coordination between the two principal organizations involved.

Past Policy Options for Addressing the Issues

Concern over public cost containment and expected growth in long term care needs has lead to three major policy responses in the past. One response has been to design programs to insure the proper use of health care resources thereby limiting costs. Examples include nursing home preadmission screening, certificates of need, and skilled-care reimbursement policy (Lave, 1985). These programs have concentrated on the nursing home where the majority of public funds for the elderly are spent.

A second approach has been to rethink the public/private nature of financing these services. New mechanisms for financing long term care have been proposed including private LTC insurance (Meiners, 1983 & 1984; Ruchlin, Morris and Eggert, 1982); health trusts (Anlyan and Lipscomb, 1985); social health maintenance organizations (Greenberg and Leutz, 1984); congregate housing (Howell, 1984); block grants from the Federal government to communities (Hudson, 1981; Merrill and Smith, 1985); and home equity conversion (Jacobs and Weissert, 1984).

New approaches to care delivery, most notably managed care by direct provision or by brokerage of services have been explored in the hope that institutional care might be avoided or delayed. Many of these methods use community-based health services (Eggert, 1980; Quinn, et al. 1982; Yordi and Waldman, 1985). Other tactics look to the family of the elderly for increased family-centered care (Cantor, 1984), recognizing the extent of informal care delivered by family members or friends. It has been

documented that these principal caregivers (PCGs) can play an important role in delaying or deferring nursing home placements in Florida. For example in a 1983 study, changes in the status of the PCG (e.g., deteriorating health, job change, etc.) precipitated 29% of decisions to place someone into a nursing home in Florida (Bradham and Pendergast, 1984).

Purpose of TEACH Services

The planned TEACH services combine these community-based and family-centered methods with nurse case management and PCG training for what is hoped will be more cost-effective community-based service to Florida's medically dependent, Medicaid eligible elderly.

Financially, this produces a complex project. As TABLE 1 shows, the Robert Wood Johnson Foundation has funded the State Coordinating Office and the Service Impact Evaluation. The VA has developed a cost-sharing agreement with HRS. The VA will barter medical-backup and training to the contracted case managers in return for services to veterans who are geographically beyond their boundaries for Hospital-Based Home Care (HBHC) Program. The VA is also funding an evaluation of the inter-agency coordination experience. Funds have been received from the Office of Human Development Services in DHHS to provide services to the veterans, since Medicaid dollars can not be used for veterans. (This funding is one example of the creative solution to regulatory challenges for such a inter-agency service project.) Florida is the recipient of a Medicaid waiver to allow reimbursement for TEACH services. There are Legislative funds to develop training materials for the caregivers. Additionally, the College of Public Health at the University of South Florida in Tampa has contributed significant support to the Evaluation Team.

These various funding sources suggest a variety of eligibility criteria for the care receiver. They must have a caregiver willing to participate in additional training and the Evaluation; be Medicaid eligible; over 64; and be certified for nursing home placement under normal circumstances (i.e., medically dependent). The caregiver can be a family member, friend or neighbor who normally provides at least forty percent of the informal care. These are restated in TABLE 2.

The two demonstration areas for TEACH services geographically include portions of HRS Districts 3 and 11. Both HRS districts, one rural and one urban, are contained within the VA's District 12.

Conceptual Model of TEACH Service Intervention

The TEACH demonstration's service design is unique among alternatives to nursing home care for the frail elderly and their principal caregivers. FIGURE 1 illustrates the intervention and TABLE 3 lists the expected outcomes of TEACH services.

As FIGURE 1 shows, several environmental factors influence the condition of both the PCG and the CR. Low income and assets may reduce access to needed health services (Aday, Anderson & Fleming, 1980). When the PCG and the CR are the only members of a household, and when there are no back-up caregivers, the PCG and the elderly person may suffer additional stress. Other living arrangement factors may exacerbate stressful conditions for both the PCG and the elderly care receiver.

Isolation, with its negative impact on social-emotional and cognitive functioning, is a major source of stress. The long hours and constant attention required of PCGs naturally cause mental and physical fatigue. Additional demands of work and family can "put a squeeze" on a PCG's caregiving time and energy. Declines in the health and physical functioning of either the CR or the PCG increase stress for both parties. These stressors negatively affect both the patient's condition and the PCG's ability to provide care (Rowe, 1985; Satariano et al., 1984). For elderly care receivers and their principal caregivers who are themselves elderly, as many are (Soldo, et al., 1983), age would tend to increase stress while lowering health status (Rowe, 1985).

The interpersonal relationship between the PCG and the CR is even more complex and fragile when the care receiver is medically dependent. TEACH services will intervene in these medically dependent situations by working to counter the negative effects of stress, poor living arrangements, and age using health support training of PCGs and case management services. Thus, improvement in the PCG's physical functioning and the quality of the PCG-CR relationship should occur, enabling PCGs to maintain their caring role longer. Any improvements in the condition of the PCG should in turn have a positive effect on the CR's condition. TEACH services will, of course, also work to influence directly the patient's condition, both physical and mental, through case management and the provision of needed services.

One significant service from the nurse case-manager will be that of piloting the PCG and care receiver through the system of bureaucratic service programs and negotiating the merging of eligibility guidelines to affect the care needed and for which the care receiver is qualified. This is case management, and it seems critical to the caregiver's retention and effectiveness. Nevertheless, recent research by Day (1985) warns that the family's capacity to carry this burden is tenuous. Recognizing the burden can be too much, TEACH nurse case managers will monitor the health of the PCG.

Potential clients will be referred to HRS from many sources: hospitals, nursing homes, community providers, and existing HRS case workers and preadmission screening analysts. Then, they will be screened for the presence of a willing caregiver, and for medical dependency equivalent to nursing home eligibility by existing Medicaid standards. Finally, they are referred to the contracted home-health provider that will deliver a specific set of services to the client and to the caregiver.

Following a thorough assessment, the nurse case managers will tailor a program of services for the care receiver (CR) and training for the PCG which fits both the patient's medical needs, and the age and abilities of the principal caregiver. The nurse case managers will also provide visible social support to the principal caregiver by monitoring the caregiver's health, the competence of their health support activities, and their impacts.

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TEACH Medicaid Waiver (Section 2176) Eligibility
TEACH clients must be 65 or older and have:
- (a) Medicaid qualification for at least intermediate level care in nursing homes,
 - (b) a principal caregiver -- either family or other -- willing to be trained and to assist the client, and
 - (c) a condition for which the PCG can be trained to monitor and provide care.

TEACH Service Hypotheses and their Evaluation

HRS and the VA are vitally interested in retaining the PCG, not causing them to become the next public supported patient. TEACH services have been designed to respond to the caregiving problems that have been visible in past research and to prepare them for adapting to future problems in their role.

TEACH's service hypotheses fall into five major, multidimensional areas. When the experience of demonstration clients is compared to a similar group of elderly people with PCGs, but who are not receiving demonstration services, several are expected, delineated in TABLE 3.

TEACH clients' long-run use of community services and institutional health services will be lower, for the same case-mix severity. Clients' use of institutional health services (e.g, ambulatory, hospital, and nursing home care) will be delayed longer and perhaps avoided. TEACH clients' lengths of stay when hospitalized or placed in nursing homes will be shorter. TEACH clients' rates of deterioration and mortality, within case-severity groups, will be slower and lower, respectively. PCGs will be retained in care giving roles longer. The implication is that the TEACH project should reduce overall expenses for the state Medicaid program.

The services are detailed in TABLE 4. Notice the specific services directed toward the PCG. In anticipation of additional stress being shifted to the caregivers, the project has consciously attempted to provide for the PCG personal support, caregiving task training and health status monitoring by health providers.

Confirming or rejecting expenditure reductions through evaluation of TEACH service impacts is critical prior to any statewide replication by HRS. But our comprehensive Evaluation will not stop there. We will also be analyzing the health and economic impacts of the project on the PCG. The evaluation will be monitoring the coordination of the two major bureaucracies involved in the VA-HRS coordination evaluation. The objectives of this companion inter-agency evaluation are presented in TABLE 5 and their conceptual relationship to the project's success in FIGURE 2.

Future Requirements of Caregivers

What are some of these future requirements of caregivers? Caregiving choices seem to be limited now, and may be broader in the future, but essentially can be summarized by three alternatives:

- a. care for the medically dependent through formal (paid) services, including home health, nursing home care, and others; or
- b. Providing the requisite care at home through family members, friends, neighbors, or other informal means; or
- c. Some combination of these mechanisms over the period of time needed.

In the future, there are several issues for the caregiver. Caregivers and care receivers should be adequately prepared for their tasks. This preventive strategy must be consistent with the anticipated problem. First, and most fundamental, general information about the aging processes, service needs, their expense and source agencies should be more readily available to individuals at ages when the information can be most effective. Some information should be incorporated

into high school education concerning human growth and development. Other information must await the later years when the means for solutions are available. Community education programs for the adult learner should be routine, and might target these same topics--caregiving tasks, service integration and case management. There are several researchable issues that must be investigated to facilitate these potential solutions. What are the topics of aging and caregiving that can be well internalized by various age groups? What age groups are most receptive? What is the best learning format? Are these training methods cost-effective to the recipient, or to society? How are they best marketed?

Caregiving training for caregivers must be widely available, cost-effective and profitable. Training modules must be efficiently packaged and economically delivered to have the largest possible impact. These educational systems must be developed with the concept of marketability, so that the private sector can disseminate the product. The efficacy of this training must be understood and documented. The planned TEACH evaluation will address this issue to the extent that standardized PCG-training modules are used. Encouraging the use of these training programs might be enhanced by tax credits for the expense, or insurance reimbursement. Issues of caregiver training efficacy, marketability, and financing must be researched now in order to properly shape future policy.

There are more specific requirements for future caregivers. For instance, whether from publicly or privately funded, family-centered caregivers will face severe economic strain in the future. Governmental funding will be more scarce. Personal funds have not been adequately invested in the past to generate enough capital to handle even current LTC expenses. Predicted health expenses (Arnett, et al., 1984) suggest a 9% average annual increase until 1990. This economic information should be provided early enough to permit investment suggesting the economic information is needed at mid-life or before to affect adequate investment. It is apparent that long term care insurance should be a part of corporate retirement and fringe packages. Some employers are beginning to see this. Such a program should be comprehensive and not just additional catastrophic insurance for Medicare recipients, as the current administration would suggest. This is an economic and policy issue of individual as well as public responsibility. On the public side, revision of tax regulations at state and federal levels should encourage this type of investment. Conversion of home equity must be explored more carefully, and creatively, since most elderly have this asset, if no others. Again there are researchable issues. What forms of private LTC insurance can be marketed successfully? What tax incentives will encourage the proper private investment and be deficit reducing as well? How much of the general public will prepare for their own care needs in this way? What barriers have prevented the use of home equity conversions?

If individuals want to protect their options for the future, they must recognize that care giving services, whether formal or informal, have direct and indirect costs associated with them. Even in the case of spousal caregiving, there may be significant indirect costs which reduce the care receiver's and caregiver's actual purchasing power. Among these opportunity costs is the foregone income of lower workforce participation, or the elimination of income if the caregiver leaves the workforce. (Additionally, we recognize the psychological, health and social costs of caregiving roles that were described earlier.) Researchable questions in this area can also be specified. What are the PCG's indirect costs? How do these costs differ across levels of medical dependency? What decisions are being made by caregivers? Are those

decisions economically rational, given both direct and indirect costs estimates? The Evaluation of Florida's TEACH Demonstration will estimate what these costs are for the caregiver.

Direct costs associated with informal care will no doubt include in-home medical equipment and training of caregivers. These will be available in most geographic markets in the future. However, some rural areas may be underserved. How can this classic maldistribution be avoided? Formal service expenses have been well documented and they lead to another PCG task that has implications for the future.

One new aspect of the caregiver's role will be managing the financial support for care. This may be more important than actually delivering care if services can be purchased more economically than produced by the caregiver. For many potential caregivers, it may be a more rewarding experience to stay in their employment scene and pay for the services that are needed. What information is useful to these informal case managers? How can businesses and agencies reach and train these care-purchasers?

Logically, in order for formal caregiving services themselves to be available, effective, financially accessible, and economical they must be profitable to the producer. Reimbursement through Medicare and other insurance schemes will help to assure service availability, since the market will respond to demand. How can insurers design their coverage to encourage the market, but to discourage over- or needless utilization? How can public and private policy be used to encourage cost-reducing technologies and services?

This raises additional issues of assuring quality and limiting fraud -- issues that have plagued all service provision to a dependent, often frail population. What protections are necessary? Which are too cumbersome?

The choices are more limited when considering non-family caregiving. Given the reduction in intact families, fewer spouses and fewer children will be available to serve as caregivers. The stereotypical "older daughter", who is now more career oriented, may especially be less available. This scenario suggests that many single elderly will rely on friends and neighbors as potential caregivers, or seek paid caregivers. The result will be a substantial market for caregiving services, beyond home health. Again, the normative experience of caregiving obtains economic consequences that must be anticipated and financed, privately or publicly.

Finally, governments will begin planning for more limited assistance programs, with severe means testing for eligibility. Evidence of this orientation exists in the Veterans Administration's recent adoption of such cost-containment policy. At a time when more services are required, the limiting of public services availability seems incongruent. The answer is a larger tax base and the trade-off of other public services or incentives for informal caregiving. Analysts could provide assistance to policy makers through studies of tax credits, creative tax structures, categorical taxation for additional services to the elderly, and mechanisms to encourage private spending in the areas mentioned above.

If we are successful in demonstrating and evaluating Florida's TEACH project, we will have some answers to the many questions we have raised, and we will probably uncover new issues as well.

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FIGURE 1

Expected Impact of TEACH Intervention

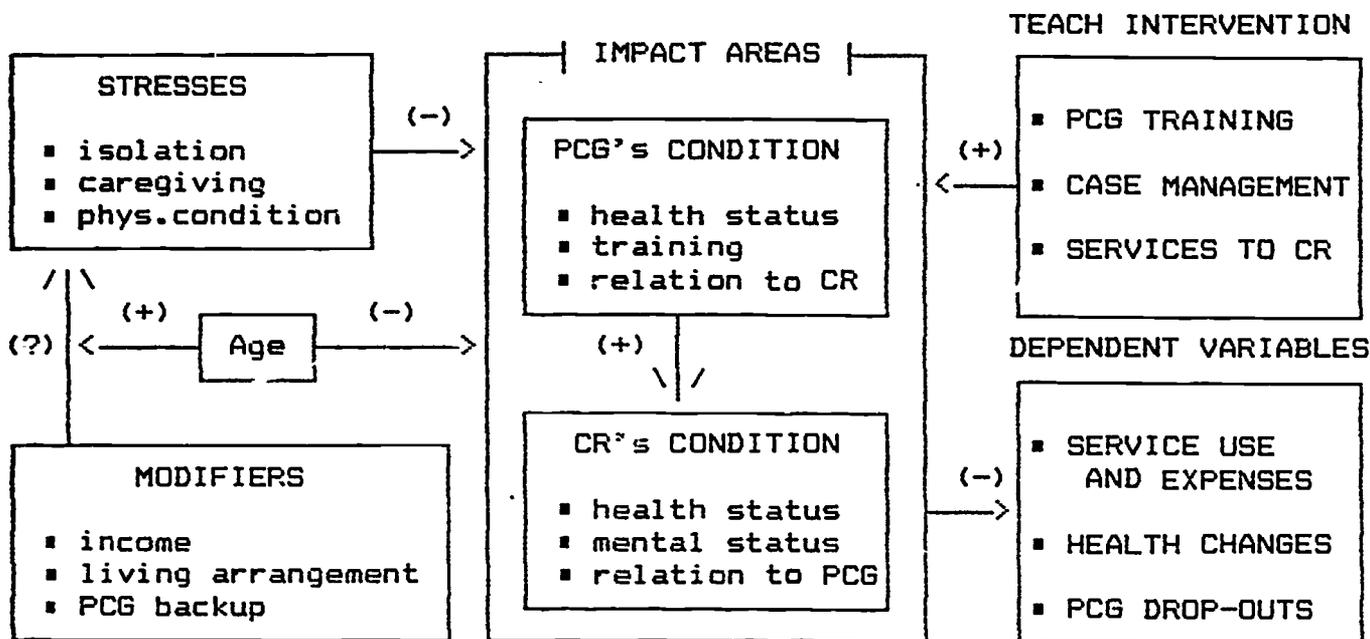


FIGURE 2

Inter-Agency Coordination Influences Under Study

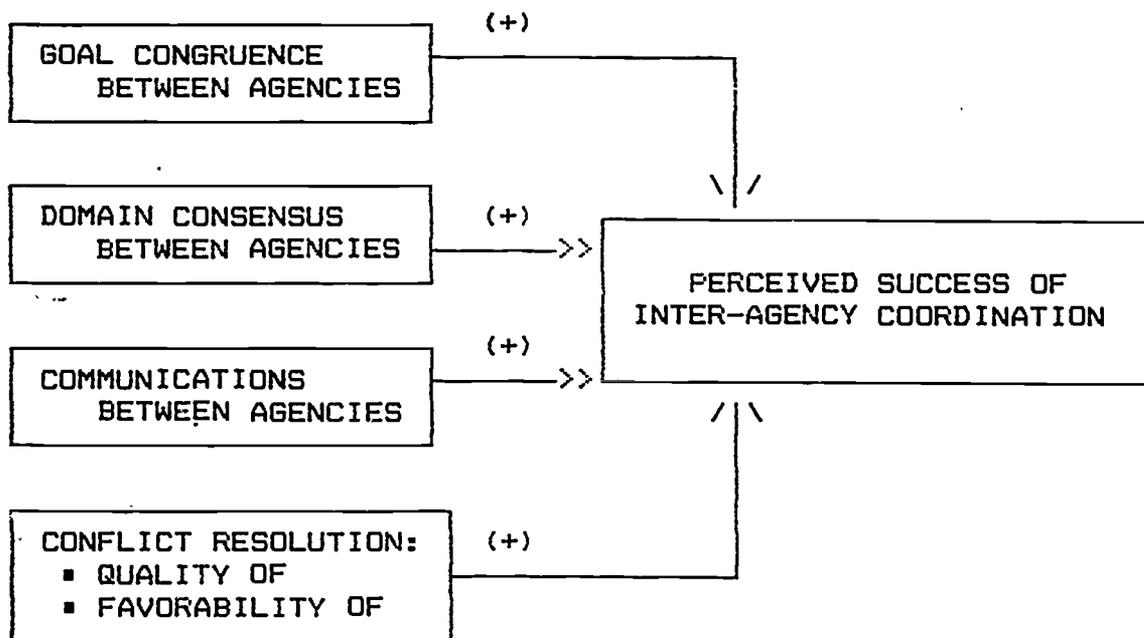


TABLE 1

TEACH Funding Sources

SOURCE:	OBJECT OF FUNDING:
1. RWJ Foundation	▪ State-level Administration ▪ Service Impact Evaluation
2. Veterans Administration	▪ In-Kind Cost-Sharing for services to Veterans ▪ Inter-Agency Coordination Evaluation
3. Office of Human Development Services, DHHS	▪ Services to eligible Veterans
4. Medicaid Waiver Funds (State and Federal)	▪ Services to Medicaid eligibles
5. Florida General Revenue	▪ Principal Caregiver training

TABLE 2

TEACH Eligibility

Clients must be:
1. 65 year old or older, and
2. Medicaid certified for minimum of intermediate (ICF) nursing home care, or more severe - or be a veteran.
Clients must have:
3. a Principal Caregiver (PCG) - a family member, neighbor or friend, willing to be trained to monitor and assist Client at home 40% or more of the time.

TABLE 3

Expected TEACH Outcomes

Clients will demonstrate:

1. Lower service use and expense for same illness severity;
2. Delayed or avoided institutional placements;
3. Shorter lengths of stay when institutionalized;
4. Slower deterioration rates and lower mortality rates over time in project; and
5. Principal Caregivers will stay in caregiving role longer.

TABLE 4

TEACH Services

FOR CARE RECEIVER (CR)

1. Assessment of medical & social service needs
2. Health status monitoring
3. Provision of in-home services
4. Brokerage of other services
5. Social & medical case management

FOR CAREGIVER (PCG)

1. Assessment of caregiving skills & training needs
2. Health status monitoring
3. Training for PCG tasks
4. Visible support for PCG
5. Assist in case management

TABLE 5

VA-HRS Inter-Agency Coordination

EVALUATION OBJECTIVES

1. How similar or divergent were the goals and objectives of TEACH among the staff involved in implementing the project?
[Goal Congruence]
2. How similar or divergent were the roles and responsibilities of each agency understood? [Domain Consensus]
3. What communication patterns were required, among which staff?
[Communication]
4. What issues became sources of conflict? How well were they resolved? [Conflict and Resolution]

CAREGIVING IN DEVELOPING EAST AND SOUTHEAST ASIAN COUNTRIES

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INTRODUCTION

This paper discusses the change in the caregiving pattern for the urban elderly in developing countries of East and Southeast Asia. These countries are selected for examination because their elderly have been hardest hit by the forces of urbanization and industrialization which have only begun in their countries within their life-time. For most of them, the world was as it had been for thousands of years when they were born; however, as they grew up, not only had traditional norms and customs waned and passed away, resulting thus a change in the kind of care they received, but they themselves also had to move away from their familiar agrarian environment to the unknown cities. Now, as they are entering into their old age, they find life entirely different from what they had seen of their ancestors, and it represents to them a most trying and difficult period.

The problems which the urban elderly in developing East and Southeast Asian countries are encountering should not of course be exaggerated. But it should be remembered that the majority of people in most of these countries, like Thailand, Malaysia, the Philippines, Indonesia and China, are still living in the villages; modern cities have only grown up there in the last three to four decades after World War II (Dwyer 1972). Their urban elderly can thus claim to be the first generation to have experienced the aging process in an industrial city. It should therefore be pertinent to understand their difficulties in order to find out the actions and policies which their countries could take to enable them to live a better life.

It has been mentioned that my discussion will be confined to developing countries in East and Southeast Asia. As industrialization has only begun in this region since the end of World War II, nearly all countries there, except Japan, are in a developing stage (Myint 1972). Although metropolises like Singapore and Hong Kong have gone some way in their industrialization process, they are not yet classified as developed. The following discussions will therefore be applicable to all cities in this region, excluding of course those in Japan, though owing to the lack of source materials, examples can only be quoted from studies carried out in Singapore, Hong Kong, Taiwan, Republic of Korea and Shanghai, where the problems of caregiving for the aged are also more acute.

While the urban elderly in these countries are first group to have grown old in a modern city, it should not be forgotten that the cities in which they live vary greatly from one another, not only in terms of their levels of economic development, but also in their traditions and cultures inherited from the past (U.N. Economic Commission for Asia and the Far East 1971). It would therefore be dangerous to make generalizations regarding the conditions of the elderly within them or the problems of caregiving they face at present. The best that this paper can do is to relate the experiences of different countries, and if similar phenomena are found, there are good grounds to believe that the care of the urban elderly is becoming a pressing issue for developing countries in East and Southeast Asia.

The Plight of the Urban Elderly in Developing East and Southeast Asian Countries

While focusing on the caregiving problems that the urban elderly in developing East and Southeast Asian countries may face, it should be pointed out that they have also benefitted from the progress achieved. Wars and disturbances have happened in some of the countries under study, but stability has prevailed in most of them and resulted in a high rate of economic development. Countries and regions like Singapore, Hong Kong, Taiwan and South Korea have grown so rapidly in their industrialism that they have now become targets of jealousy (Chen 1979). As a whole, living standards in most cities in East and Southeast Asia have been raised, absolute poverty reduced and most people are now enjoying a longer life span and greater material affluence than ever before (Wong 1978). The caregiving problems to be described as besetting the urban elderly are thus emphasized for the purpose of identifying the actions which these countries and regions must take to improve their lives; it does not mean that the urban elderly are necessarily worse off than their ancestors or their counterparts in the villages.

Nevertheless, the urban elderly under examination are no doubt living in an unprecedented age and facing changes unheard of in their societies in the past. One of the obvious changes is that more and more of them are no longer living with their grown-up children. In Hong Kong, it was found that about one in four of those aged 60 and above were either living alone or staying another elderly person (Hong Kong Government 1977:2). In studies on the living pattern of the urban elderly (aged 65 and over) in Taiwan, though more than 75 per cent of them were found in the early 1980s to be living with their grown-up children, there was an obvious trend for an increasing number to live alone (Luo 1985:8-11). In a survey on the senior citizens (aged 55 and over) conducted in Singapore in 1982, it was found that 81.4 per cent of them were still living with their children, but the rest were either living alone or with spouses or other persons (Singapore Ministry of Social Affairs 1983:12). In South Korea, according to information released by the Ministry of Health and Social Affairs, the number of three-generation households had decreased from 26.7 per cent in 1986 to 21.0 per cent in 1972, though it was stressed by the Ministry that "the ties between parents and offsprings are still close and strong even in cities" (Korean Ministry of Health and Social Affairs 1979:43). In Shanghai, a survey conducted in the early 1980s revealed that of the 3,380 households with pensioners interviewed, 78 per cent, or 2,637 households had pensioners living with their children (Fudan University 1981:31). To sum up, it seems obvious that the norm of this region is for the urban elderly to live with their grown-up children; there is even shame in not doing so, though the trend is set for an increasing number of them, either out of choice or necessity, to live alone or with persons other than their children.

So far as developing countries are concerned, whether or not the elderly are living with their children still determines to a great extent their possibility of receiving care from the latter. The fact that the majority of the urban elderly in this region are continuing to live with their children indicates that the support of the elderly remains largely a family matter, and this will help not only in reducing the difficulties of the aging process, but also in relieving the burden of the state in supporting a great number of lonely elderly (Nursberg and Osako, 1981). However, in view of the rising number of nuclear families, it will be useful for governments to institute measures to encourage children to live with their elderly parents so as to maintain the prevailing mode of co-dependence between generations.

The formation of nuclear families may have only deprived a small portion of urban elderly in this region of the opportunity to live with their children, but setbacks in their economic status are bothering all. Rather than holding the reins of economic resources as they used to do, the urban elderly in this region are now economically dependent on either their children or the state for a living and this affects the kind of care received by them (Thompson 1983). Recent studies conducted in some of the cities in this region showed that very often the poor consisted largely of elderly persons who lived alone. For example, nearly two-thirds of the 62,000 public assistance cases at the end of 1985 in Hong Kong applied because of poverty in old age. Other research findings further showed that the failure of the urban elderly to support themselves in old age and their subsequent need to depend on their children often induces an adverse relationship between the two generations (Chow 1983). Anyway, it is a common phenomenon for the urban elderly to be economically dependent. In Taiwan, a recent survey revealed that only 15.8 per cent of the elderly interviewed were able to support themselves, while 21.2 per cent depended on the support of the eldest son and 59.3 per cent had the burden shared between the children (Kiang and Chang 1985:44). The same situation also existed in other cities: a survey in Singapore reported that 84 per cent of the elderly interviewed regularly received financial and material support from their relatives (Singapore Ministry of Social Affairs 1983:25) and in South Korea, a national survey conducted in 1974 found that 56.7 per cent of those who had retired expected financial support from their children (Korean Ministry of Health and Social Affairs 1979:42). But in Shanghai, as the majority of the elderly there are receiving retirement pensions, they are usually less dependent financially on their children and some of them are even reported to be regularly giving money to children who earn little (Shanghai Committee on Aging, 1984).

Nevertheless, the general situation of the urban elderly in this region is that most have been relegated to a subjected economic position with some even having to resort to assistance from the state. This situation has arisen partly from the lack of retirement benefit schemes in most countries of this region (Wadhawan 1979). Even for those which have introduced social insurance or provident fund schemes, the benefits given can seldom form a reliable source of financial support for the retired. For example, members of the Central Provident Fund in Singapore can only obtain on retirement what they had accumulated and the sum is acknowledged to be inadequate for the needs of the entire old age period. In Taiwan, again only lump sum benefits equivalent to a few years' salary (one month's salary for every year of coverage) are given to employees who retire under the Labour Insurance Scheme (Kaim-Caudle 1983); as a result, only 13.3 per cent of the elderly interviewed in a survey in Taipei were reported to be solely living on their retirement pensions (Shiau 1985:11). Indeed, other than the examples mentioned above, the majority of employees working in the cities in the East and Southeast Asian region are not yet provided for their old age. The fact that only a small proportion of the urban elderly are entitled to the rights of financial independence implied that most have simply to fend for themselves or to seek support from their children. Of course, problems would not have arisen if they could either save up enough while working or their children were prepared to support them. However, as the present group of urban elderly were usually paid meager wages while working and had heavy family responsibility, their saving capacity was often very low. Besides, most did not see the need to save up for old age as they had never seen their ancestors do so. But when it comes to seeking support from children, evidence indicates that the younger generations are increasingly less and less willing to shoulder the responsibility of supporting the old (McGillivray 1980). To summarize, most urban elderly in this region are economically dependent because their countries are not providing them with adequate income protection schemes and often the elderly themselves have not

made preparations for an old age in which they can be independent financially. This has forced many of them to accept a subjected economic position in both the family, and the society, and has created a high incidence of poverty among the elderly population.

For the urban elderly in this region who still believe that old age should be honoured, an economically dependent status is indeed hard to bear. The esteemed position the aged used to occupy in the past was supported to a large extent by the economic power they had as head of the household or owner of the land. However, with the changed circumstances and the present elderly being forced to depend on their children for financial support, they suffered an inevitable loss of status as they have not only to admit inadequacy but also accept a minor role and weakened functions (Ikels 1983:3-35). Studies on their life-style in fact revealed that an entirely new image of the elderly is now emerging, very different from that traditionally held of them. There is now little evidence to show that the urban elderly are still venerated by members of their families and the society. The Government in Singapore has recently found it necessary to reiterate the teachings of Confucius and to stress the importance of filial piety (Richardson 1982). To follow that up, the Ministry of Health of the Singapore Government, in a report on the problems of the aged published in 1984, stated that one of the elements of a policy for the aged must include a strengthening of "the traditional family system, filial piety, respect for the elderly in the family and general reverence for old age" (Singapore Ministry of Health 1984:5). In another study on the changing life-style of the elderly in Hong Kong, it was found that those interviewed had usually a very low image of themselves and they expressed a strong feeling of isolation and uselessness (Chow and Kwan, 1984). In South Korea, where industrialization has only had a short history, the Korean Ministry of Health and Social Affairs, while stating on the one hand that "The traditional values of the Korean family are characterized by the filial piety based on Confucianism, the hierarchical order centered around the unshakable position of the patriarch," admitted on the other that "with the spread of the idea of efficiency and rationalism demanded by the industrial society, the traditional family-centered values have come to lose much of their significance" (Korean Ministry of Health and Social Affairs 1979:42). Even China, in a paper presented at the World Assembly on Aging in 1982, emphasized that it was time that the elderly be given a proper role to play in their families and in society (Chinese National Committee on Aging 1983:229-232).

It is thus fair to say that other than financial inadequacy, another problem that the urban elderly in this region are facing as related to the issue of caregiving is the loss of a role to play in their families and in society. The Chinese National Committee on Aging in a national conference on the elderly held in August 1984 has put up a slogan stressing that caring for the elderly means that they must be "financially supported, cured when ill, have a proper role to play, have opportunities to learn and things to enjoy (Yu 1984)." Indeed, an important thing for the elderly is that they must be able to see themselves as being useful. Studies so far indicated that most of the urban elderly in this region have often failed to find a meaning in life. The National Survey of Senior Citizens in Singapore in 1983 found that most common leisure activities of the elderly were watching television, listening to radio and going for walks (Singapore Ministry of Social Affairs 1983:). A study conducted in Taiwan in 1983 found that out of 636 elderly respondents 141 admitted that they felt lonely (Kiang and Chang 1985:47); though the number seems small, it has to be remembered that to be lonely in old age is still a shame in a Chinese society. The situation appears to be even worse in Hong Kong where a survey found that nearly two-thirds of the 441 elderly interviewed agreed that "to be old is to wait for the coming of death (Chow and Kwan 1984:48)." Another study also found that elderly abuse

is becoming a pressing issue in Hong Kong (Chan 1985). Indeed, the life of the urban elderly in developing East and Southeast Asian countries has much to be desired. The task facing policy makers for the elderly is not merely a matter of securing adequate support for them, but also creating a life which the elderly will find meaningful.

The needs of the urban elderly in this region, as revealed by the research studies, are varied and go beyond material support. In the study conducted in Taiwan by Kiang and Chang (1985:44), the greatest need of the elderly was found to be psychological support, followed by health services and financial assistance. The Committee on the Problems of the Aged in Singapore also stressed the importance of "continued employment and participation in family and community activities (1984:5)" by the elderly. The South Korean Government, in a statement on social development strategies, stated that it should be "concerned with human alienation in a modern industrial society, a society in which people are spiritually starving even in the midst of material affluence." The strategy to be adopted should thus be "a well-balanced development between the material and spiritual aspects of life (Korean Ministry of Health and Social Affairs 1979:45)." In summary, most countries and regions under examination seem to agree that in meeting the needs of the urban elderly, attention must be paid to their material and non-material aspects. This emphasis is attributed to the fact that, despite the general absence of adequate income protection schemes for old age, the majority of the urban elderly in this region can still have their basic needs met as they continue living with their children; but they find it much more difficult to adjust to a fast changing city life as they are seldom assisted to do so. Surveys conducted in Hong Kong and Singapore indicated that, as a result of their inability to lead an active social life, most of the elderly are forced to stay at home with their grandchildren. These duties which now fall mainly on the elderly used to be performed by their daughters or daughters-in-law who often choose to go out to work after marriage. The contribution of the elderly in household chores is in fact very valuable, serving as a stabilizing force in the family, but it is seldom recognized and the elderly are subsequently relegated to a position equivalent to domestic servants. Besides, there are other restraints which prevented the elderly from leading an active social life; for example, community activities especially tailored for the needs of the elderly are scarce and even non-existent. So inactive are the elderly that despite their growing numbers, they have hardly made their presence felt except by those supporting them.

Policies and Strategies to Help the Urban Elderly

It should be pointed out that the support of the urban elderly has only become a public issue in the East and Southeast Asian region in the last ten years or so. In Hong Kong, a working party to look into the future needs of the elderly was established by the Government in 1972 (Working Party on the Future Needs of the Elderly, 1973) and the relevant policy paper on the development of social services for the elderly appeared in 1977. The South Korean Government in the late 1970s still thought that "It will be beneficial to the Korean social security system to promote the still remaining social ethic of the support of old parents and respect to the elderly, and to leave the support of old parents to their grown-up offsprings primarily and then to expand the social security to the supporters (Korean Ministry of Health and Social Affairs, 1979:46)." In Singapore, the needs of the elderly were not discussed until a few years ago when in 1982, the Government set up a Committee on the Problems of the Aged. The Committee subsequently conducted a survey to find out the conditions of the elderly and made recommendations of government action (Vasoo and Tan, 1985). In Taiwan and Shanghai, the needs of the elderly have been given greater attention in recent years; a law

to promote the well-being of the aged was promulgated in Taiwan in 1980 (Hsu, 1985) and the Shanghai Municipal Government has recently improved its care for the elderly through the services provided by its Civil Affairs Bureau (Shanghai Committee on Aging, 1984).

Since policies to support the elderly have not been formulated in the above countries and regions until lately, relevant measures and services instituted are thus few and rudimentary. Generally, these countries and regions are still relying to a large extent on the family system to provide the major portion of care and support for the elderly. Even in Singapore and Hong Kong, where resources are more readily available as a result of rapid industrialization, social services for the elderly are still found lacking in most instances. The overall situation can be summarized by Little's (1982:16-17) four hypotheses regarding the provision of social services for the elderly, namely: the universality of services given by families and relatives; the existence of institutions such as private homes for old people for those who can afford to pay; the precedence of public institutional care over community care; and the general lacking of home-delivered services to supplement family care. A further analysis of the data available suggests that four different stages can be identified regarding the development of care systems for the elderly in the countries and regions under examination. These four stages are:

Stage 1: Care comes entirely from families and relatives. It is morally obligatory for children to support their elderly parents and failure to do so is regarded with shame.

Stage 2: Private or charitable institutions for old people are established and accepted as an alternative to family care, especially for the lonely elderly.

Stage 3: Public provision of social services is acknowledged as necessary to supplement family care. The "open care" concept is introduced with community support services provided side by side with institutional care.

Stage 4: Attempts are made to adopt an integrated approach towards the support of the elderly, including a balanced development of case assistance and services-in-kind, and a combination of public and family efforts.

There is no denying that each country may have its own particularities, but those under examination seem to have followed a similar pattern in developing their policies regarding the support of the elderly. Hence, in the initial stage when the care of the elderly became an issue of public concern, these countries usually reacted by emphasizing the importance of family support and the undesirability of public intervention. In a policy paper on social welfare services published in 1965, the Hong Kong Government stated that "social welfare services should not be organized in such a way encouraging the natural family unit to shed on the social welfare agencies, public or private, its moral responsibility to care for the aged or infirm (Hong Kong Government, 1965:5)." The South Korean Government in the late 1970s held the opinion that "it is questionable whether to keep on the social security program in such a way that may further the disintegration of the family in general (Korean Ministry of Health and Social Affairs, 1979:46)." Statements like the above two can also be found in policy papers of other countries in this region when the care of the elderly first attracted public attention. However, as more and more old people needed care outside the family system, institutions for the elderly began to increase in number, established mostly by charitable organizations; these were also gradually accepted as a viable alternative to family care. At a later stage,

the demand for support services for the elderly outside the family system was so great that it necessitated public intervention.

By and large, most of the countries under examination have now entered stage 3 where the care of senior citizens has been accepted as a government responsibility, though the role of the family system is very much emphasized. For example, a national policy for the elderly recommended in Singapore in 1981 aims at combining the different roles of the government, the family and other voluntary and charitable bodies in support of the elderly. The law promulgated in Taiwan to promote the well-being of the aged also recognized the responsibility of the Government in the care of the elderly. The Seventh Five-Year Plan (1986-1990) recently adopted by the Chinese Government stressed that "We shall put in place a social security system ... continue to foster the fine tradition of mutual assistance among relatives, friends and neighbours (Chapter 51)." In summary, the present question for the developing countries of East and Southeast Asia is no longer the necessity or otherwise of government intervention, but the extent to which the government should assist the family and the level of resources the government should allocate for such purposes.

In fact, despite the short history of public provision, the range of social services now available in some of the countries and regions under study has increased so rapidly that it is comparable to developed countries in the West. For example, in Hong Kong where a "care in the community" approach has been adopted since 1973 to enable the elderly to remain in their own homes, a wide variety of community support services have been introduced including community nursing, hostels, day care centers, canteen and laundry services, home help and social centers (Hong Kong Government, 1977). Other cities in this region, like Singapore and Shanghai, have already emphasized that the relevant policies must not be confined to the establishment of institutions, though their community support services for the elderly are still limited. The Shanghai Municipal Government has been active in recent years in organizing cultural and recreational activities for the elderly; educated retired persons are also provided with opportunities to contribute towards the society's well-being by acting as reformatory school counsellors, translators and advisors (Fudan University, 1981:35). The national policy for the elderly recommended in 1984 in Singapore also proposed to "give older workers more employment options such as part-time work, flexitime, work that can be done at home and work on an alternate day basis (1984:6)." It appears that national policies for the elderly in this region are seldom confined to merely the necessary institutional and community support services; emphasis is often placed on helping the elderly to truly become members of the community to which they belong.

Thus, while social services for the elderly may still be found lacking in the cities of this region, relevant policies so far formulated show certain common characteristics. Two of them are worthy of detailed discussion. The first special feature is the emphasis on the continued importance of the family system in caring for the aged. This arises partly from the fact that due to the lack of resources, the family system is simply indispensable in contributing towards the care of the elderly. However, the emphasis seems also to be based on a genuine belief that only within the family system can an elderly person find true satisfaction and happiness. It can even be argued that so long as this belief is held by the majority of the people in East and Southeast Asia, a national policy for the elderly can never ignore the functions of the family. The second special feature is the importance given to both the material and non-material aspects of the lives of the elderly. As the South Korean Government once put it: "Issues of individual happiness or social welfare must fundamentally be more a matter of metaphysics, ethics, and value judgements than a matter of visible materialism

(Korean Ministry of Health and Social Affairs 1979:45).¹¹ The non-material aspects are no doubt abstract and intangible and are thus difficult to define and fulfill. Nevertheless, planners in countries of this region who do not pay attention to the spiritual needs of the elderly will fail to come up with a satisfactory policy. At the present stage, it may be difficult to assess the extent to which policies on the elderly formulated in developing countries of the East and Southeast Asian region can actually satisfy the material and non-material needs of the elderly, but they certainly have their own special purposes to achieve.

CONCLUSION

Since the urban elderly in developing countries have only grown in numbers in recent years, it is not surprising that services provided for them are short in supply. The examination of the conditions of the elderly living in major cities of developing countries in East and Southeast Asia reveals, however, that although the majority of them are living with their families, the difficulties they encounter are still enormous. The subjected economic position which most of the elderly now occupy has not only greatly reduced the respect shown to them, but has also made them feel inadequate and isolated. Life to a substantial proportion of them is indeed dull and meaningless. Furthermore, the elderly are often deprived of a positive role to play in their families and in the society.

The policies being enforced in countries of this region to support the elderly have mostly been introduced in recent years; retirement benefit schemes form in most cases the only measures implemented on an extensive scale, but the amounts given are admittedly inadequate. As for community support services for the elderly, their importance has only recently been accepted as a necessary supplement to the functions performed by the family system. A further analysis of the relevant policies reveals that in caring for the elderly, most countries under examination have not only stressed the important role of the family, but also the necessity to satisfy both their material and spiritual needs. The extent to which these countries are able to achieve these objectives has yet to be assessed; in the meantime, measures to provide adequate care for the many elderly who have never thought of growing old in an industrial society will be most urgently called for.

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ECONOMIC INCENTIVES FOR FAMILY CARE OF THE ELDERLY

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Projections in the United States, and in many other countries in the world, indicate that both the number and proportion of the elderly will increase. This is especially true of the oldest of the elderly, those who are most impaired and dependent. This trend, resulting from lower birth rates, medical advances, and greater longevity for more individuals, has many consequences for those countries faced with such population trends. The probability is great for increases in health and social service resources for the elderly, as well as increases in public-supported welfare payments and allowances.

These increasing demands for resources for and financial benefits to the aged must be borne by governments faced with low economic growth, extensive unemployment, competition for other public expenditures (for domestic support), and/or increasing monetary demands for national defense. Whether the form of government is a full-fledged welfare state or one based upon individualism and more limited government responsibility, the problem of competing demands for limited resources exists.

It is believed that there is a governmental trend toward encouraging increased family involvement in the care of the elderly, predicated upon economic, moral and social beliefs, which are or will be encouraged by public policy in many countries. This trend may well have adverse consequences for the elderly and their families and is based upon faulty assumptions regarding economic savings and an out-dated conceptualization of the family system. The themes for governmental policies of family care for the elderly include economic incentives to encourage or sustain family care for the aged. Such policies, without service support, are believed to be potentially harmful to families and the aged.

Family care of the elderly is not being argued against. Indeed, it is the family which has been the major provider of financial assistance, emotional support, personal care, and housing for the elderly (especially the most vulnerable and impaired) around the world. What is being argued against, though, are governmental policies which "force" the aged upon their families, without the necessary economic or formal support services to adequately minimize adverse consequences of care on the families as well as the dependent aged relatives. Additionally, governments need to acknowledge changes in demographic characteristics and cultural values which are resulting in fewer adult children to act as caregivers and more elderly not having family members who can be competent caregivers, or having family members available in the geographic area.

BELIEFS

The apparent move to emphasize or encourage family care of the elderly through official governmental policy rests upon a set of popular beliefs. These assumptions focus upon economic pressures on public spending and on strengthening the bond between the aged and their families.

Direct or indirect financial assistance to induce families to take responsibility for their elderly relatives is based upon the assumption that

such assistance will ultimately reduce government spending for the elderly in the areas of community resources, sheltered housing, welfare assistance, and institutional care.

There are those who believe that government policy is necessary to reconfirm the moral (or religious) obligation of filial responsibility. Proponents of this view believe that family responsibility was unquestionable in the past, but has been altered (has declined) as a result of industrialization, Westernization, urbanization, and technological advances. A further assumption often made is that the elderly desire and expect their adult children to care for them. Such beliefs can be based upon traditional cultural patterns and expectations. The elderly had cared for their parents and, it is reasoned, look forward to being cared for by their children.

Ample research supports the view that care of the elderly by their families is commonplace. Inasmuch as family care is generally provided, and increases with the increasing impairments of the elderly relatives, it is believed that government should help families provide care through various types of mechanisms. A corollary to the above is that while some families genuinely desire to care for their elders, other families need to be induced to provide care. It is reasoned that some families cannot afford the expenses resulting from the care to (or housing of) an elderly relative. These family members may wish to be helpful, but--because of limited financial resources, limited housing space, additional responsibilities (such as young children) or because both adults in a household are working full-time--do not see such assistance as feasible.

Family assistance is seen to be more effective than that provided through formal assistance, whether private or public. That is, the family setting is seen preferable to congregate housing, family activities are more beneficial than those of formal programs, and care in the home more humane than in institutionalized or age-segregated settings.

Based upon any one or combination of these assumptions, governments and their citizens may conclude that policies are necessary to ensure that family responsibility is maintained or is encouraged. Over time and in different countries, two major themes have existed as mechanisms to strengthen family responsibility for elderly relatives: economic incentives to encourage families to care for their elderly and requiring family responsibility.

ENCOURAGING FAMILY RESPONSIBILITY

Direct or indirect financial assistance for the care of elderly relatives has been discussed in the United States. Among various possibilities are those for tax incentives (Steinitz, 1981) or direct cash subsidies (GAO, 1982). While the United States Government has no national policy for direct payments for families caring for elderly relatives, several states have either demonstration or modest programs for reimbursing families for some of the expense incurred from care to an elderly relative (GAO, 1982). Whether in tax relief or in cash allowances, families are encouraged to "care for their own." The State of Florida, as one example, provides minimal subsidies to families or friends to cover basic support, medical expenses, and special care for dependent older persons. While national policy has been proposed, presently no such programs for family support exist in the United States.

Another method which family care is ensured is by requiring family care of the aged through state or national policy. Such a policy has been

discussed in the United States as one method of cutting state and federal costs (and reaffirming filial responsibility). In the past, in America, public assistance (generally of a financial nature) was withheld from an elderly person until or unless it was determined that there were no family members or that relatives could not afford to give needed care to the dependent and needy elderly relative.

Although other countries may be eliminating such policies, Gibson (1984) points out that United States policy is leaning toward "some filial responsibility for the costs relatives incur in nursing homes. Although several such measures have failed in Congress, Medicaid statutes have recently been reinterpreted by the Reagan Administration to allow states to force adult children and other relatives to pay the cost of nursing home care" (p. 178).

ASSESSING ASSUMPTIONS

The point has been made that two themes exist for officially linking the family and their elderly relatives and that these themes emanate from several assumptions and/or beliefs. This section will provide an assessment of the assumptions which will lead to the conclusion that the assumptions are based upon faulty premises. As had been mentioned, the view that family responsibility is morally, ethically, or religiously correct rests upon value judgements which can be neither proven nor disproven by empirical standards. As such, the views are idiosyncratic to individuals and societies. It is a faulty premise upon which to base a policy which will affect all citizens. The assumption that the elderly desire to be the responsibility of their families, too, is subject to question. While family care and residing within the home of a family may be preferred to institutionalization, ample research findings suggest that independence from family is preferred (Atchley, 1980).

With increasing impairments, resulting in an older person being less able to provide for one's self, the family may increase its participation in the life of the older person. But to think that one's family has no choice but to provide care (through subtle or overt pressure by government policy) may lead to dismay or humiliation by the older person. Indeed, family care may not be desired because of past or present conflicts with family members. Additionally, such pressure for family care may necessitate older persons moving from their dwellings to that of relatives, and this could result in movement from one part of the country to another (where adult children live). If family care is encouraged by policy and is the only alternative, the older person is--thus--forced upon a relative or relatives. The elderly, no less than any other group, do not wish to be burdens.

Neither do family members necessarily desire to care for an elderly relative, nor can they necessarily afford the "cost" of providing care. Elsewhere (Rosberg, 1984), "costs" to families providing care to elderly relatives have been discussed as including physical, social, psychological, and psychosomatic consequences as well as financial strains. The possibility that family members may be as impaired as the care recipient (such as an elderly child, sibling, or spouse) should not be forgotten.

The basis of kinship obligation for the care of elderly relatives as a result of genuine desire and affection has been questioned (Jarrett, 1985), and some have speculated that such care can emanate from feelings of guilt for providing care. As Brody (1985) states: "guilt may be a reason that people assert that they and their own families behave responsibly in caring for their old, but that most people do not do so as was the case in the good

old days" (p.26).

Family incentives for care of the aged have been discussed by others as being counterproductive; as formalizing what should be informal relationships. "A financial payment system may change family values. Payment for care formalizes the family's obligations and its role in caregiving" (Arling and McAuley, 1983, p. 306). In considering family incentives, Shor (1980) offers a similar conclusion: "The rhetoric of incentive, broadly applied over a period of time, might in the long run subvert filial attachments and responsibility" (P. 37). This is a dilemma which has not been resolved.

It can be that those families who want to care for elderly relatives are already doing so. Other families have no recourse but to offer care and shelter, due to the lack of alternative resources. Families do not need incentives, but rather supporting services to assist them in that which they are already doing. Quoting Brody (1985): "There are suggestions for 'incentives' for families to care, implying that they need to be induced, rather than helped, to do what they want to do and have been doing" (P. 27).

Thus, supporting services to those who care for elderly is the preferred alternative to incentive proposals. In the United States, community resources (often publicly-supported) can include adult day care, home health care, chore services, and transportation programs. "One of the most necessary services for families providing direct care to their ill older relatives is some form of respite care to enable the caregiver to have a night away from home or take a vacation" (Gibson, 1984 p. 72). Respite care is available for families in many countries, but is still relatively scarce in the United States.

The conclusion to be reached is that families need non-economic support and not economic incentives. "Non-financial factors, such as restrictions on personal time and emotional strain, weigh heavily on family caregivers and financial payments may not be effective in relieving these social and psychological pressures" (Arling and McAuley, 1983, p. 305). This is certainly true if the economic benefits to the family are but a pittance and neither induce nor adequately meet the financial expense of care borne by the family.

CONSEQUENCES

Implementing policies which encourage or require family support of the elderly are not only predicated upon faulty assumptions and beliefs, but also can result in consequences quite contrary to the aims of such proposals.

Financial Savings. Economic cost-saving, if any, may well be offset by economic burdens to families which--in turn--will result in the need for other forms of governmental expenditures. The implementation of a national (or even state) program which either mandates or encourages (through incentives) family care of the aged will have potentially high administrative costs.

Family Pressure. The consequences of family incentive programs can exacerbate problems in generational relationships within families. The result--inadequate care for the elderly--will hardly be that which is sought by such programs.

An Informal care system already burdened, or otherwise stressed, and coerced into caring for an elderly person may be unable to adequately provide for the care needed by the older person. Adverse consequences to the physical and mental health, and the overall quality of life, can follow.

The ultimate adversity to an older person by a burdened caregiver may be elder abuse (Kosberg, 1983). Whether out of anger or frustration, the dependent older person may be especially vulnerable to abusive behavior. Efforts which mandate or otherwise force families to care for the elderly can place the aged into the hands of those who are unmotivated, ill-suited, and unable to provide necessary and humane care. Incentive programs, too, may encourage family care of the elderly, not out of compassion but out of economic gain. In both cases, poor care, if not abusive behavior, can possibly follow.

Social Changes. Family incentive programs for the elderly presuppose the existence and availability of family members. Government policies which limit its focus only to family care discriminates against those elderly without families or those whose families are unavailable to provide care. So, too, do such policies fail to conceptualize the family in light of social changes.

As Brody (1981) has discussed, women (generally daughters) are the major caregivers of the elderly in the United States. This is true, also, for the care of the aged in many nations (Gibson, 1984). Public policy which overly relies on families as caregivers for dependent elderly will have to acknowledge changes in the family constellation. Multiplicity of changes occurring in many countries can include lower birth rates which result in fewer children to support elderly relatives, decisions made by couples not to have children, the decline of extended families, more divorces and remarriages which can work to obscure family responsibility, multigenerational family networks where children of the elderly are themselves old, and the continuation of geographical mobility of both the young and old, (including emigration).

And, of course, public policies will have to reflect changes in the role of women, whereby younger seek careers outside the home and older (women after raising their children) seek education or careers. This phenomena exists not only in the United States but also in many other countries as well, such as Japan (Maeda, 1983), Great Britain (Greengross, 1981), and Sweden (Little, 1978).

CONCLUSION

Although all the information is not yet in, the conclusion reached is that family care of the elderly cannot be viewed as a panacea. There are insufficient data on cost savings. There is ample evidence that pressures on already-burdened families may result in adversity to elderly family members. There is a need to acknowledge changes in the family as an institution, and the availability of family members as caregivers. And there is a need to consider those elderly who are without families.

Yes, some families can benefit from financial assistance, but what is needed are greater supporting services for the family who voluntarily provide for the care of elderly relatives. The social and psychological consequences on families caring for elderly relatives cannot be compensated for by (often meager) tax benefits or cash allowances. Families need resources which will assist, support and temporarily relieve them in the care of their elderly relatives.

In conclusion, then, policies which formally encourage or require family care of the aged are not seen to be effective, but rather are possible detriments to natural informal care systems. Publically-spon.sored resources are necessary to augment and supplement family care, and for those elderly who are without informal support systems. Forcing the aged upon their families, as the official policy of a nation, especially without necessary supporting services, will be potentially inequitable, ineffective, and harmful to both the aged and their families.

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CAREGIVING AMONG MIDDLE AND LOW INCOME AGED IN HONG KONG

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INTRODUCTION

Of the various ethnic groups, the Chinese family is viewed as a closeknit social unit from which its members derive support, security, and a means for meeting needs. The tradition of valuing the aged in Chinese society had been the subject of many popular stories and prose. In the old days, since long life was a symbol of blessing from heaven, therefore having an old member in the family will bring blessings to the family and clan, hence he or she deserved special privilege and protection. Senile decline was taken as a matter of fact and the family would come together to cope with the problems, however marginal the level of subsistence. Furthermore, as filial piety is stressed in Confucius teaching, children who honoured their parents were praised and held as models for everyone in the clan. The aged represented life experience, knowledge, authority, and status. Under such cultural influences the status and prestige of the aged were high in traditional Chinese society. That is why China has been described as a "gerontocracy" because of the position of the elderly in the family and the general veneration of the aged in the Chinese world view. In spite of physical infirmity the elderly were able to continue to perform useful and socially valued roles. Thus, caring for the elderly posed no social problem in the traditional Chinese family.

The Hong Kong Context

Hong Kong, like many cities in Asia, has experienced tremendous socio-economic growth in the last two decades which has transformed the city from a basically agrarian community as well as a small trading port, to a highly urbanized city and international finance centre in the East. The most striking change has been a sizable growth in the total population, from 0.6 million to 5.5 million. This has been accompanied by increasing numbers of elderly, who are now a larger proportion of the total population than earlier. According to census statistics, the proportion of elderly aged 60 and over in Hong Kong increased from 7.4% (293,273 persons) in 1971, to 9% (398,180 persons) in 1976, to 10.2% (507,018 persons) in 1981, to 11.6% (640,000 persons) in 1986 and is expected to rise to 12.6% (737,100 persons) in mid-1990 (Census and Statistics Department, 1986:7-12). This size of the elderly population has increased by 73% since 1971 while the overall population has only increased by 27% (Government Secretariat, 1982:5). It is projected that the number of elderly people will grow to 800,000 in ten years' time. The life expectancy of males born in 1981 is 71.7 years and of females 77.5 years (Government Information Service, 1982:15).

In other advanced countries, the problem of the aging of the population, with its attendant needs for medical, housing and welfare provisions, has been faced squarely and various precautionary measures adopted. With increasing urbanization and industrialization, environmental constraints such as small housing units and western influences, the family unit is coming under great strain and old people are being compelled to rely on government for a greater measure of support than was necessary hitherto. However, this

has not been the case in Hong Kong.

Before 1945 social welfare policies and programs in the Crown Colony of Hong Kong were little developed. British colonial policy tended to be pragmatic and remedial, reflecting a Poor Law philosophy which aimed to return the underserved poor to their countries of origin, and at keeping the Colony from serving as a Mecca for poor Chinese and the poor of other Asiatic countries. The Second World War and the Chinese Revolution initiated a change process and forced a new focus on social welfare problems, including those of old people. There is no doubt that aging brings with it many problems, one of the problems is the caregiving aspect.

Within this paper, we will specifically look into the caregivers. Findings from recent studies (Chow and Kwan, 1986; Kwan and Chow, 1985; and Kwan, 1986) will be used in order to highlight some of the attitudes, feelings, and relationships of caregivers and elderly in middle and low income level in Hong Kong. Though there are many different ways to define 'old', here in Hong Kong, we generally refer to those of 60 years of age and over as 'the elderly'. For traditionally the 60th birthday was an occasion for special celebration because, in a sense, the individual was reborn on this birthday. The traditional Chinese calendar consisted of sixty year cycles; thus, the 60th birthday marked the beginning of a new calendrical cycle. Every tenth subsequent birthday was also regarded as a 'big birthday' and was ideally marked with a banquet or festive meal with family and friends. The 60th birthday also signified elevation to the status of elder.

Two Exploratory Studies on Aging

What does it mean to grow old in contemporary Hong Kong? What are some of the relationships between the elderly and their caregivers? One must recognize in the past people have tended to idealize old age in Hong Kong. The aged persons had been perceived as being very content, highly respected, adequately looked after by their families, valued by their children and grandchildren, and were allowed to indulge their dependency and authority needs--quite a contrast to less positive views of old age in Western society. When the Hong Kong Government planned its services for the elderly in 1977 it worked more or less on the same assumption that "Chinese society has a traditional healthy respect" for old people. The Chinese family remains a tightly knit one and the majority of old people are cared for by their families (Hong Kong Government, 1977). This assumption may be applicable to those elderly members of the society who live in closely knit families and neighbourhoods. And, as long as the number is small their needs can be met by their immediate families, relatives, and friends. But for the majority of the aged in Hong Kong situations have changed, somewhat drastically, in the last twenty years.

First, the impact of changes in social structures, particularly the family structure, has been tremendous. While there is a strong belief in family solidarity and interdependence, the nuclear family in Hong Kong can no longer fulfill the many functions which were formerly assumed by a traditional clan-oriented family network. Secondly, the shift from an agricultural to an industrial-urban community affects the basic conditions of life for all ages, and has implications for both the young and the old. For example, changes in the economic structure affects needs for training, extended periods of education, and further education for adult workers. The old generation must accept the younger generation's wish to 'get ahead' and to be independent.

With the emphasis placed on youth and productivity in an industrial-economic system, the society continues to give priority to the younger group in terms of allocation of resources and social provisions. For instance, the public housing policy in Hong Kong enforces policies that married children must leave the family to set up their own household. The aging parents are thus forced to live separately from their adult children, whether they like it or not. In this way, family ties are weakened by this physical separation reinforced by a government which upholds Western ideals and values.

When decreased attention is paid to the positive values of maturity and other potentials of mature adults, the generation gap becomes wider. Intergenerational conflict is said to be responsible for the isolation of the old and for their exclusion from the protection and care of the family. Disengagement is in fact an enforced reaction of the elderly persons as they sense rejection by their adult children and junior colleagues. The result is a feeling of alienation which is destructive of the old people's right to social integration.

The above seems to describe the common problems faced by our Hong Kong aged members today, yet there has been little empirical research to back up this general impression. How valid are these problems and to what extent do they affect our elderly? No doubt, some of the elderly persons are having a tough time, but many may face old age with a different attitude and life-style, reflecting the variety of aging patterns in Hong Kong. In order to fully understand the older members of our society, here in this paper we will specifically look at two recent studies which were carried out under the auspices of the Department of Social Work, Chinese University of Hong Kong, and the Elderly Division, Hong Kong Council of Social Services.

The first comprehensive Hong-Kong-wide study of the low income elderly took place in 1983. With the assistance of the Census and Statistics Department a sampling frame of 723 families with old persons and with a total household income of \$3,500 or less a month were drawn, from which a random sample of 578 were selected for the study. At the end of the visiting period, of 623 households approached, 441 were successful interviewed. The questionnaire, which consists of 70 items, focused on getting information on the background of the elderly interviewed; their employment and financial conditions; the health conditions of the elderly; the life-style of the elderly; and questions directed at the caregivers of the elderly.

The second Hong-Kong-wide study of the middle income elderly took place in 1986. With the assistance of the Association of Private Homes for the Elderly a sampling frame of 192 private and profit-making homes for the elderly were drawn, from which a random sample of 96 were selected for the study. At the end of the visiting period, of 69 homes approached, 443 elderly respondents and their caregivers were successfully interviewed. The questionnaire, which consists of 80 items, focused on getting information on the background of the elderly respondents; their current financial condition; relationships with family members; opinions about the home; their nursing care needs; and their personal care needs.

The Findings

1. Nature of Relation between the Elderly Respondents and their Caregivers: From the low income elderly sample, 82.5% indicated that they stayed with their family members (e.g. spouse, son or daughter, son- or daughter-in-law). As to the middle income group, 69.3% also indicated that before they were admitted into the private homes, they were staying with their family members. On an average, those not on their own were

living with one child and one grandchild and less than half were with their spouses. And it was not uncommon for some families to have elderly respondents living with their in-laws. However, respondents' households seldom consisted of members who had no direct blood relationships, such as friends.

The above findings reconfirm the 1978 study (Hong Kong Council of Social Services, 1978:34) that more than 59% of the respondents lived with their spouse, son, daughter, grandchildren, son- or daughter-in-law; the 1982 study (Department of Social Work, 1982:19) that 75% of the respondents stayed with their family; the 1983 study (Chow, 1983:48) that there were 59.5% respondents living with family; and the 1985 study (Social Welfare Department, 1985:7) that 53.5% applicants were living with family. Therefore it is obvious that most of the Hong Kong elderly were staying with their family members, and family members inevitably play a key role in providing care to the elderly. Then the question becomes: Do the caregivers alone tackle the problems or do they need sufficient and adequate supportive services in the community to back them up?

2. Frequency and Kinds of Help: Regarding the kinds of help the caregivers rendered to the elderly respondents, from the low income group, the most frequent services were escorting them to go out, washing, shopping, cleaning, and cooking. But it is important to note that even among the above items, help was seldom provided on a regular basis. As regards direct cash assistance, only 52% of the caregivers reported that they regularly gave money to the elderly respondents. Other than cash (23%), interestingly the elderly also contributed back to the family in other ways, such as house keeping (76%), doing household chores (68%), and looking after the grandchildren (39%).

On the other hand, the middle income group suggested that the main reason for their admission into private homes was nobody in the family cared about them (88.5%) when their physical health deteriorated. As to the monthly cost of staying there, 66.8% of the elderly respondents were financially supported by their children.

Furthermore, when we looked at the willingness of the caregivers to care for their elders, in the low income sample, the caregivers did not usually regard this as a unacceptable burden, although around 10 to 20% did express their unwillingness to carry out such duties. This was particularly true when the elderly were not capable of self-care. And 64.1% of the middle income elderly respondents were sent to the private homes by their family members. Does that mean the caregivers in the middle income level did not wish to look after their aged? Or were there differences because 80% of the elderly needed intensive medical and nursing care which caregivers hardly can cope with?

3. Relationships with their Caregivers: Among the low income elderly, the average number of visits which the caregivers made in one month was 12.9 times. In regarding to their relationship, 28% of the elderly considered their relationship very good, 40% good, 30% fair, and only 2% poor or unsatisfactory.

In the middle income group, 47.7% considered their relationship with their family very good before admission to the private homes, 33.4% good, 5.6% bad, and 1.6% very bad. After admission to private homes, 46.7% still considered their relationship very good, 35% good, 5% bad, and 1.1% very bad. With this group, 47.9% of caregivers made a visit at least once a week, and 37.6% at least once a month to the elderly in

the private homes.

While we could in no way check the sincerity of these remarks, we believed that owing to the fact that most of these caregivers were the elderly respondents' spouses or children, plus the strong normative value in the society of respecting and caring for the aged, it was only natural for the caregivers to describe their relationship with the elderly respondents as a bit better than it might actually be. Hence, a fair relationship might probably be denoting a condition more on the negative than the positive side. No one will deny the fact that providing care to a frail elderly member in the family is not an easy task itself, it makes us wonder what will happen to both the caregiver and the aged if the caregiver was overburdened?

The Controversy of Community Care

In Hong Kong, the family remains the chief supporter of the elderly. According to the 1981 Population Census, of the 491,740 elderly population (aged 60 and over) living in domestic households, 12.1% were living alone and 2% living in non-nuclear family households consisting of unrelated persons. The remaining 85.9% (422,516) were living with family members or relatives. However, among these 85.9%, 1% (73,379) were living with only one other member (and 35,982 of these were living with a person also aged 60 years and over). Nonetheless, it can still conclude that the extent of family support to the elderly population is still strong in Hong Kong. As already highlighted in the earlier discussions, family members play a major role in caregiving their elderly. But will they be provided with enough support from the community or government to sustain this effort? Now let us briefly examine the community care concept advocated by the Hong Kong Government in recent years.

With an attempt to draw up policies and programme plans for services for the elderly in Hong Kong, a "Green Paper on Services for the Elderly" was published by the Government in late 1977 as a result of a joint effort between the Government and the Voluntary Sector. The quite comprehensive green paper eventually became an eight page chapter in the white paper, "Social Welfare into the 1980's", published in April, 1979. The stated objective of providing services for the elderly is "to promote the wellbeing of the elderly through care in the community and by the community" (p.14). The Government's strategy will be three-fold: firstly, to provide a range of community services and improved cash benefits that will encourage families to look after their elderly members, or which will enable old people on their own to live independently, and in dignity, in the community for as long as possible; secondly, to provide residential institutional facilities for those who for health or other reasons, can no longer live with their families or on their own; and thirdly, to promote a better understanding of the process of aging so that old age can become a more positive and productive period, not only for the elderly themselves, but also for the community at large.

As the basic philosophy of community care is to retain older persons' self-esteem, respect, and a sense of belonging to the community at large, the caring of the elderly has to be kept in the community and with the community. This means that the community will provide assistance to meet the needs of the elderly at the local level. Therefore the continuation of social interaction with the family members, kins, and friends, and the new development of social relationships between housemates and neighbours is significant to facilitate community care. Up to now our total number of social centres for elderly and multi-service centres for the elderly are falling far short of the demand expected.

The next question is whether the elderly tenants are being cared for and being looked after within the community? There must be someone who pays attention to the elderly's needs and concerns. Our Government has planned to act as "formal service providers" with a range of social services as supplement to the informal care. But only up to the end of 1984. Then the Social Welfare Department initiated for the first time direct residential services to elderly clients (Kwan, 1986:201). Otherwise all other services for elderly were provided by voluntary agencies.

The last question relates to who are actually caring for these elderly? The members of the helping network and their degree of involvement will give an indication if the elderly are being cared for in the community or cared by the community. In past years many social critics already challenged the Government on the community care slogan and raised questions about its effectiveness. We all know that independence is one of the fundamental qualities that gives a man a sense of himself. Independence in old age is closely linked to problems of economic security, work, and health. Without a willing and active government in elderly welfare, how much can the community sustain the whole responsibility of caring the elderly?

FINAL REMARKS

Reintegrating the elderly into society will depend on the formulation of social policy which provides for services to meet specific needs, but is also a way of developing a network of viable and functional social relationships around the old person. Care for the elderly is not just to offer them institutional care when they do not have a family to fall back on, or to offer them medical care when they fall ill. These concepts extend the meaning of community care far beyond domiciliary care, implying the existence of interdependent social relationships which enhance the sense of dignity and self-worth of those involved. Within such a network of caring relationships, the elderly will be helped to withdraw from their primary social roles without feeling unwanted and useless. From this point it is possible for the elderly to shift from an emotional investment in family roles and occupational roles to other social roles in the community.

The Programmed Plan for the Elderly, endorsed by the government in 1979, is quite a comprehensive document, which looks into the housing, medical, employment and social needs of the elderly. Balanced and coordinated development of provisions in these different fields should ensure a more secure life for our growing number of senior citizens and demonstrate the community's care and respect. However, what has been done in the seven years since falls far short of the demand and the stated policy objectives.

Another general observation is that though it is the aim of the Government's social welfare policy to enable the elderly to remain as long as possible as members of the community by providing them with the appropriate services, findings do not show that this policy has benefited the elderly who were living with their families. This failure to make an impact may be due either to the insufficient supply of the services so that they were not available to those needed them or to their irrelevance in achieving their intended aims. To us, the first seems to be more plausible. In other words, Hong Kong, like other countries adopting similar approaches, has been paying only lip-service to the "care in the community" concept. Thus, while promises are made for services to be provided to enable the elderly to remain as long as possible as members of the community, the Government has never succeeded in making available the necessary help and assistance. This results in families remaining the primary provider of care for their elderly members, and they have to shoulder the responsibility all by themselves.

This poses enormous difficulties for both the elderly and their families.

In our opinion, the most positive and meaningful way to assist the increasing number of the elderly population is to improve existing policy plans, to provide enough supportive service for caregivers, to preserve and draw out the knowledge and contribution of the willing and able elderly, and to change the conception of the elderly from being the "waste or leftovers of society" to being the "energy of the society". Only when the elderly feel that they are contributing to the rest of society will they be a group of happy and healthy senior citizens.

With the prolonged shortage of community support services for the elderly, it could be foreseen that this would not only make the "care in the community" concept a mockery, but also leave many families with no choice but to put their frail elderly into institutions, therefore defeating the purposes that the concept aims to achieve. On the other hand, there weren't enough public institutions for the family to rely upon, therefore they have to send their elderly to private profit-making ones. And unfortunately up to now there is no legislative control on these homes, since a Code of Practice was only published by the Social Welfare Department in October 1986 serving as a general guide for the operators (LO, 1986:2-3).

For example, planned development in residential and day care facilities has been delayed time and again, on account of financial stringency. In 1985-86, only the three planned aged hostels and three care-and-attention homes have been completed. But less than half of the five planned multi-service centres, two day care centres and nine social centres were materialized, and these are of vital importance to the stated policy of promoting community care for the elderly. Another example is the woefully insufficient number of infirmary beds in hospitals, forcing a number of elderly who need that level of medical care to remain in care-and-attention homes, thereby depriving others who need a home place of the opportunity.

Apart from service provision and coordination, the Government should rightly be charged with a responsibility for long-term planning for our aging population. For instance, without a comprehensive pension scheme or a central provident fund, the community will have to shoulder an ever-increasing demand on its resources for the subsistence of the elderly. At present, over 60% of Public Assistance recipients are elderly, and Old Age Allowance (for people over 70) takes up 25% of total welfare expenditure.

Furthermore, while it is evident, as revealed by the previous studies, that the family system is still playing the major role in providing the elderly with the necessary care, the kind of care provided is far from satisfactory. Findings showed that most families were only supplying their elderly members with the bare means of living. As a result, the lives of the elderly with families were often as dull as the lonely ones and socially they were no more active. It seems obvious that if the elderly are to be encouraged to lead a more active social life, help must come from the society/government rather than the families alone.

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POTENTIAL FOR ABUSE IN CAREGIVERS

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BACKGROUND

Human aging is a developmental process with its own developmental patterns. For most old people, it is a period of increasing dependency, materially, physically, socially, and emotionally. Dependency in old age however does not necessarily contribute to a social problem. In traditional Chinese society, caring for the elderly has been a family responsibility. This is because "interpersonal relations are central to the basic philosophy of an agrarian society...The relations with one's kinsmen are the most important of personal relations, and kinship ties are the basic units of society." (Wong, 1975:7). Within such kinship units, the old are well provided for and taken care of. Furthermore, in an agrarian society, the status of old people rises, old age being synonymous with wisdom. The young traditional depend upon the old for knowledge and guidance. The elderly in rural areas generally do not experience actual retirement. Rather, responsibilities decrease as age increases, but status and position in society remain secure.

Today in Hong Kong, industrialization and urbanization have been going on at a rapid pace over the past 25 years. They have been responsible for the prosperity of Hong Kong but also have their negative effects, creating acute housing problems, reducing the strength of family and kinship network and placing an undue emphasis on technology, commerce and industry. Overcrowding in small family units and the economic independence of youngsters and women are breaking up the traditional Chinese family structure. The present population in Hong Kong is estimated to be around 5.5 million, according to the projection of the 1986 By-Census (Census and Statistics Department, 1986:7-12), the number of people aged 60 and over is estimated to be 640,000 in mid-1986 (11.5% of the population) and is expected to rise to 737,100 in mid-1990 (12.6% of the population). In fact, the proportion of old persons in the population rose from 4.8% in 1961 to 7.4% in 1971 and to 9% in 1976 and to 10.2% in 1981. Hong Kong people nowadays live longer than previously; the life expectancy at birth in 1980 is 71.7 years for men and 77.5 for women. The life expectancy at the age of 60 in 1980 is 17.5 years for men and 21.5 years for women (Government Secretariat, 1982:10). It is projected that the number of elderly people will grow to 800,000 in 10 years' time. The fact that people live much longer than they did 20 or 30 years ago says much for the improvement of living standards and health service in Hong Kong during this period but there is no doubt that aging brings with it many problems. Although there are many different ways to define 'old', here in Hong Kong, we generally refer to those of 60 years of age and over as 'the elderly'.

In such a rapidly changing society, some members begin to neglect the elderly. In their own homes, institutions and homes of their relatives, some of the elderly feel unimportant, as if there is no real purpose in life. But of far greater consequence is the importance of elderly abuse of caregivers at home. In Hong Kong, with its predominantly Chinese inhabitants, where filial piety is treated as a sacred norm, the term "elderly abuse" may sound unfamiliar. However, the increasing number of abandoned elderly in hospitals

should not be unheard of to the public (Boschman, 1981:29). One reporter even estimates that the figure of abandonment amount to 50 to 60 in public hospitals while it's around 30 in private hospitals per month. The incident cited above is only one of many unveiled by the local newspapers from time to time. With 98% of the Hong Kong elderly population (Government Secretariat, 1982:7) residing at their homes, either with relatives or not, the magnitude of this problem deserves more attention and research. Within this paper, we will highlight several observations from two recent studies on elderly abuse (Chan, 1985) and elderly suicide (Kwan, 1986) in order to generate some discussions on the issue.

Two Exploratory Studies

In order to draw a real picture of elderly abuse at home in Hong Kong, the School of Social Work of the Hong Kong Polytechnic in collaboration with the Working Group in the Study of the Elderly Abuse in Hong Kong, Services for the Elderly Division, the Hong Kong Council of Social Service, undertook the first comprehensive Hong-Kong-wide study of the elderly abuse in 1983, there being no research of any sort on this topic prior to this. The said study consisted of case study and survey. The Key Informant technique (a total of 222 panelists were selected) was employed to develop the 24 indicators of elderly abuse which eventually regrouped under the main categories of physical abuse, abuse in daily living, financial abuse and psychological abuse. With the assistance of the Census and Statistics Department, a sample of 1,000 households with at least one person aged 60 or over was randomly selected for the survey. Interviews were completed with data from 637 households. On the other hand, with the assistance of the social welfare agencies, a sample of about 100 abuse cases were randomly selected and studied retrospectively to identify their common characteristics. Interviews were completed with data from 93 cases.

The other study on elderly suicide was aiming to examine the suicidal phenomenon of elderly in Hong Kong during the last 4 years (1983-1986). Secondary Data Analysis approach (through one major local newspaper's daily reporting) was adopted in order to trace back all the reported elderly suicide cases within past 4 years. A total of 385 cases were recorded and basic information on age, sex, methods of suicide, reasons of suicide, result of suicide, and either stay with family or not were obtained.

Observations

1. Age, Marital Status and Educational Attainment: By looking at the five most common abuse conditions in the case study shown below, we can see that most of the Hong Kong cases are not that violent in extreme as compared to the western world:
 - 1). Nearly 36% of elderly being put under all kinds of daily inconvenience, cause on purpose (e.g. wetting the elderly's bed/body, or blocking the elderly by putting up various obstacles, etc.).
 - 2). Another 28% of elderly being frequently assaulted (e.g. slapping, kicking, striking with fists, bruising, twisting to injury, etc.).
 - 3). Around 22% of elderly being forced to do overloaded household chores (e.g. cleaning, washing, cooking, taking care of children, etc.).

- 4). About 20% of elderly being deprived of savings or properties through improper means (e.g. threatening stealing cheating blackmailing, etc.).
- 5). Finally, 17% of elderly being passed around like a 'human-ball'.

The abused elderly are found to be old people of ages 70 or above. The widowed are particularly dominant. With regard to educational attainment, the abused elderly are reported to be less educated than the general elderly population. In comparison to the suicide sample, more than 42% are aged 70 or above. Though there is no proof that getting older will invite a higher chance of being abused, the fact is that when one's general socioeconomic background is relatively lower, then he is more vulnerable to being neglected or abused by the caregivers.

2. Physical Health and Body Functioning: More than one-third (37%) of the abused elderly are reported to have some sort of physical disabilities. Within which 68.5% suffer from chronic disease of one kind or another (e.g. Rheumatism, High Blood Pressure, Cardiac Disease, etc.), also 10-30% manifest handicap in areas of performing the daily living activities (e.g. getting in and out of a bed, taking a bath, preparing meals, etc.).

From the suicide sample, the most outstanding reason for committing suicide is illness (61.9%). This finding reflects that there were life crises for the elderly (especially in the aspect of deteriorating physical health) and the caregivers (especially in the area of taking care of a sick old family members). These adjustment problems in life crises situation may trigger abusive behavior.

3. Interpersonal Relationship: As reflected in the case study, it is revealed that over half (58.9%) of the elderly have never had any visitors in comparison to 13.7% in the survey sample. Which half of the elderly (51.6%) are reported to have no pastime at all, only 3.6% of the elderly in the survey sample have no favorite pastime. On the other hand, half (47.3%) spend their leisure hours all alone as compare to 16.1% in the survey sample. In addition, a large proportion (89.6%) are found to have unsatisfactory relationship with their household members. Also most of the elderly (case sample, survey sample and suicide sample) are staying at public housing. These environmental factors (e.g. crowded living quarters or physical isolation, etc.) play a major part in bringing about neglectful and abusive behavior.
4. The Abuser: As expected, family relationship is one of the significant factors that has correlation with elderly abuse. The family relationships as found in the survey sample are far better (only 2.9% with bad family relationship) than that among the abuse cases (89.6%). The case study shows that daughters-in-law (46.2%) and sons (34.4%) are the most commonly identified abusers in abuse cases. The potential abusers to be of lower educational level, higher age group of the population and come from less well off households. In addition, over three-quarters (80.6%) were cases in which the elderly lived with the abusers, and with half on them (50.6%) relying on the latter's financial support as well.

In viewing the suicide sample, 66.4% have family members in Hong Kong and 58.8% are actually living with their family by the time of their suicide. This tells us that a person who relies on someone else for his care is more likely to be neglected and/or abused.

Also it is found that 4.9% of the households in the survey with at least one elderly member consider overall elderly abuse conditions acceptable. In terms of the projected elderly population in mid-1984 (594,800), the corresponding number of elderly people at risk of being abused would be 19,153 and 39,138. With respect to financial abuse, 10% of the households in the sample or 45,621 to 73,339 elderly persons are suspected to have potential elderly abusers. Concerning the situation of passing the elderly person like a human-ball, the findings show that 19.8% of the respondents in the sample or 99,391 to 136,149 elderly people are subject to this type of abuse.

DISCUSSIONS

When traditionally the Chinese family was the main support system to the elderly. Now neither the family nor the aged are prepared for the coming of this life period, even less prepared is the government of Hong Kong. While differential social and economic opportunities associated with age, sex, and class differences tend to intensify generational conflicts and tensions between the individual and the society, such changes also affect the personal adjustment of the old among us, since they are more vulnerable than the young to social and economic hardships. Under the continual pressures of urbanization and industrialization the social needs of the aging group will be especially acute in the years to come, in Hong Kong as in elsewhere.

The loss of primary roles, both occupational and familial, is generally recognized as critical for the aged. Feelings of being unwanted and of being superseded by younger people, coincident with the lessening of physical vigour and vitality, can be terribly damaging to the self-image of old people in a society characterized by a strong achievement orientation. They may lead to extreme loneliness and isolation of the old people.

As indicated in the abuse study, overall abuse is found to be related to the following characteristics of the elderly: educational attainment, employment status, relationship with family members, financial independence and social involvement. If the elderly has high educational attainment, is not employed, enjoys harmonious relationship with other family members, is financially dependent on other relatives and has high social involvement in terms of having more relatives in Hong Kong, is visited by other people more frequently and more pastimes, the respondents tend to consider overall abuse acceptable.

The specific types of social adjustment needed are based, of course, on the problems which confront each individual old people. But we can't ignore the kinds of burdens and pressures bear by the caregivers. Without sufficient supportive systems in the community to support the caregivers, no wonder there were more and more abused cases in the society, also the rising of the elderly suicide rate in recent years. The drastic rise in suicide rate among the elderly and the other tragedies involving isolation, neglect and abuse of the elderly in recent years should have warned us of the need for quick action. Within this paper, based on a preliminary analysis of the data from two recent studies, it led to a tentative conclusion that our elderly people and their caregivers are not responding to change in an adjusted manner because the social institutions in Hong Kong are not offering them the required support. Therefore we may argue that the potential for abuse in caregivers is structural or societal rather than personal.

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**THE CENTRALITY OF COMMUNICATION IN MAINTAINING
INDEPENDENCE IN THE ELDERLY**

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One of the most salient features of development is the unrelenting struggle for independence. This is observable in the lower animals wherein the young soon learn to forage on their own and protect themselves. It is observable as well in educational institutions as the dependent unit seeks departmental status. It is most certainly observable in the case of geopolitical areas that strive for recognition as independent nations, and also in the case of such organizations that seek even greater identity and independence by breaking the bond of a common and well established language and promoting through their schools the use of languages indigenous to their areas. And how very observable is this struggle for independence in the developing human organism as we are assured by the three-year-old that "I can do it myself": by the teenager who views adult cautions as vestigial remnants of a by-gone age and as litany only to be respectfully tolerated; by young adults who are determined to make their marks; or by the older adult who wants to be sure that the home is paid for, the savings account is adequate, and medical and hospital insurance are sufficient. The motivation for independence, at whatever age or stage of human or organizational development, finds expression in the individual's or group's ability to communicate its individual or collective will. Not only is communication essential in the establishment of independence but also in the maintenance of that independence as well. Successful and improved communication is a source of power and as such can assist the individual in controlling his/her environment and destiny throughout the later years. It should be noted at this point that, as suggested by the Frances Hellebrandt (1980) study, "physical independence is only part of independence..." One of the implications of this statement is that independence is in part a function of successful communication through which individuals are able to exercise their wills irrespective of the environments in which they live. The centrality of communication to the quality of life was highlighted in one response to the survey of advantaged elderly of First Community Village in Columbus, Ohio made by Hellebrandt (1980). The question was "what makes for good quality survival?" A significant part of the response was "the satisfaction of relating to others."

Recognizing of course that there are many factors which contribute to the erosion of independence in the elderly, such as ill health, insufficient financial resources, loss of a private means of transportation and others, the situation of the older person who is victim to any of these factors is made worse by a communication problem or simply by the lack of skills in communication. Although we know of no empirical studies that specifically address this question we would risk making an hypothesis that goes as follows: there is an inverse relationship between communicative abilities

and skills and dependence of the elderly. It is not our intention to set forth proof for support of this hypothesis but hopefully to present sufficient evidence to make such an hypothesis tenable.

Talking and listening are taken for granted by most of us throughout life, and not until something impairs these functions, as frequently occurs among the elderly, must we become concerned. It is then that specialized assistance is often sought with the hope that intervention might in some way restore language/speech or hearing. When these processes become impaired the psycho-social disequilibrium that results can be devastating and dehumanizing. When arms or legs become impaired there are usually reasonable substitute strategies for coping that can be developed, however, when an individual is deprived of the very processes that are so important to human social interactions as are speech/language and audition, the interventions called for are often even more difficult and complex. Food, shelter, health care, transportation, and others are all tremendously important areas of concern to older people, but are without much meaning in the face of disordered communication that deprives them of the easy give and take necessary for successful interpersonal relationships or even for enjoying the outputs of the mass broadcast media, for that matter.

POTENTIAL PROBLEMS

Those disorders that frequently accompany the aging process and contribute heavily to breakdown in interpersonal communication are:

- hearing loss
- auditory processing
- speech and language problems associated with stroke or other neurological dysfunction
- the dementias and
- laryngeal excision.

To this list should be added yet another potential contributor to communication breakdown (not a disorder as such) and that is:

- knowledge of and attitudes toward the elderly by those with whom the elderly must interact on an interpersonal level.

Hearing Loss

1. How prevalent is it among the elderly?
2. What are the psycho-social implications of hearing loss to the elderly?

According to the National Center on Health Statistics (Figures based on the 1980 National Health Interview Survey-and reported by Punch in ASHA, April, 1983) the prevalence of hearing impairment between ages 65-74 years per 100 non-institutionalized persons in the U.S. was 24.10% (3,430,852) and for those 75 and over, 55% (3,087,095) - or for all over 65 years 29.27%. One can expect that the institutionalized elderly would show higher prevalence rates with figures up to 80-90% (Maurer, 1984).

The prevalence of handicapping hearing impairments increases with age and becomes about 10 times as great in the declining years of life than it is at the threshold of adulthood. Hearing impairment is the third most prevalent chronic condition among the non-institutionalized elderly (U.S. Congress, 1986). The psychosocial consequences of hearing impairment are

many and contribute to increased dependence of the elderly. There is rather well documented evidence that hearing impairment is associated with:

- unnecessary embarrassment
- fatigue
- increased irritability and tension
- avoidance and withdrawal
- increased vulnerability to bodily safety
- boredom
- marital tension
- rejection
- increased vulnerability to promises of restored hearing
- depression
- acting upon misinformation
- a perceived negativism on the part of the elderly
- diminished opportunity to assume leadership roles and
- reduction in the amount of information available to the elderly to process (Oyer and Oyer, 1979).

Think of each of these in relation to its effects on quality of life.

Auditory Processing

Successful processing of auditory events such as speech and other important non-speech signals calls for more than an intact peripheral auditory system. It calls for integrity as well of the central auditory nervous system. The neuronal changes which can affect intelligence, memory, recall, and learning are diffuse and can complicate what otherwise might be thought to be a peripheral problem. With central aging effects one observes the older person who for all intents and purposes can hear what another is saying but fails to understand what is being said (Hayes, 1981). When someone else must interpret that which is being said to the older person, the integrity and independence of the older person is immediately compromised.

Speech And Language Problems Associated With Stroke Or Other Neurological Dysfunction

As for speech and language disorders among the elderly, we see by statistics from the 1981 Survey of Stroke (NINCDS) that (as reported by Maurer) virtually 3/4 of all acute strokes occur in those who are 65 years and over and that some speech and language impairment is present in almost 60% of non-comatose stroke patients. Senile dementia of whatever etiology also adds substantially to the language problems seen among the elderly from less than 5% among the general non-institutionalized elderly to over 60% among those in institutions.

Estimates show that articulatory problems and dysarthrias constitute almost 20% of the communicative problems of the institutionalized elderly and vocal problems slightly more (21%).

Laryngeal Excision

As for alaryngeal speakers, we have available some rather general figures relative to age showing the mean age to be at 55 years (Intor. Assoc. of Laryngectomees, 1975). Latest American Cancer Society figures show white males age 65 constitute 45% of white males of all ages for cancer of the larynx and white women 42% of white women of all ages. Furthermore, the average annual percent change for males 65 and over is +1.3%: for women 65 and over, +7.1%. Data were not available for the other racial and ethnic

groups (Baranovsky and Myers, 1986).

Whether it is a speech or language problem (associated with aphasia, speck, apraxia or dysarthria) brought about by stroke or dementia of other neuropathology, or whether it is loss of voice associated with cancer of the larynx, the independence of older persons is dramatically curtailed the moment that they lose the oral ability to communicate fully and freely, their feelings, needs, and desires. They not only become substantially more dependent but dehumanized in the process.

Knowledge Of And Attitudes Toward The Elderly By Those With Whom The Elderly Must Interact On An Interpersonal Level.

Not only do actual pathologies in the elderly cause breakdowns in communication and erode their independence but so may the attitudes of those who function as caregivers within the family or in institutions.

It has been shown (Butler and Lewis, 1982) that prejudice toward older people begins in childhood. Little wonder that studies bear out the fact that there is considerable misunderstanding on the part of the general public concerning the effects of aging and consequently negative attitudes toward aging. The often quoted Louis Harris Poll (1975) showed that 71% of the public felt that little respect is shown adults over 65 years of age. Only 21% of the 4254 respondents viewed persons over 65 as being very useful to anyone. However, we were pleased to learn from the most recent White House Conference on Aging Report (1981) that negative stereotypes regarding aging have begun to diminish. We can only hope that there is an improved attitude among professional workers as well. Studies indicate that psychiatrists surveyed (Butler, 1975) held negative attitudes toward the elderly and that students of social work, law, and medicine not only lacked knowledge about the elderly, but that none of the students gave as their first preference working with the elderly in their future careers. Seventy-four percent of social work students placed the old people in third or fourth preference and 88% of the medical students indicated their preference for working with older people was only as a last resort (Geiger, 1978). Surveys of occupational therapy students (Mills, 1972) and clinical psychology students at the doctoral level (Wilensky and Barmock, 1966) also showed preferences for working with younger people.

Curious as to how students of Communications Disorders ranked with respect to knowledge and attitudes regarding older persons, several colleagues and I developed, and administered an attitudinal inventory and Palmore's (1977) Facts on Aging Quiz to a representative sample of undergraduate and graduate students (Oyer and Wall, 1986). Our findings relative to the "knowledge" aspect were somewhat similar to those found by Palmore. On the attitudinal aspect we found that attitudes toward elderly were really quite good but the older persons were ranked second from the bottom as a group the students would prefer to work with professionally. Against the backdrop of some confusion and contradiction in the literature concerning the attitudes of nursing personnel toward the elderly, a recent study of attitudes of long-term care nursing personnel toward the elderly (Chandler, et al 1986) suggests that all three groups studied, RN's, LPN's, and NA's were basically neutral or positive in attitude toward older people. They did find however that the RN's attitudes were significantly more positive than those of the LPN's and NA's.

NEED FOR SENSITIVITY OF CAREGIVERS

It is not only important that caregivers be expert in the care they provide the elderly but also of paramount importance that this care be rendered with a sensitivity to the special problems that interfere with interpersonal communication among the healthy as well as the disabled elderly.

A very splendid and practical set of suggestions for caregivers rendering communication care to geriatric patients has been developed by Dr. Rick Bollinger of the VA Hospital in Miami and his colleagues. They have carefully worked out care plans for aphasic, dysarthric, confused, and hearing impaired elderly patients (Bollinger, et al 1977).

Not only is the quality of care enhanced by successful communication between the caregiver and the elderly but also the quality of life of the elderly. For successful interpersonal communication is at the very core of the human experience of the elderly irrespective of their health status or the environment in which they dwell.

RECOMMENDATIONS

In closing we would like to make several recommendations aimed at developing a greater understanding of the importance of successful communication to the enhancement of independence among the elderly.

1. Infuse materials on interpersonal communication, speech-language and hearing changes related to aging, and disorders of communication often associated with the aging process, into the curricula of all those who will serve professionally as caregivers to the elderly.

2. Provide in-service training workshops to caregivers in both short and long term care institutions for the elderly focused upon the importance of communication with older people, problems of communication often associated with aging, and strategies useful in facilitating communication with the elderly.

3. Carry out instructional and counseling sessions for the family members and significant others of communicatively impaired older people within the framework of senior citizens centers or other appropriate institutions in local communities.

4. Foster the development of international exchange through the medium of perhaps an academy or collegium that would provide a forum for worldwide dissemination of information concerning the communication problems associated with aging and the rehabilitative procedures found to be most successful.

5. Encourage research specifically directed toward the relationship of types and severity of communication problems and their effects on maintenance of independence by older people.

Successful communication is crucial to the integrity of older people, to their feelings of self-worth and their social efficiency. Thus every effort should be made to keep the lines of communication open.

For communication is central to successful transactions throughout life and particularly so for the elderly who are often set apart from the main stream of society.

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INFORMAL CARE AND THE USE OF FORMAL SERVICES: ARE THEY RELATED?

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INTRODUCTION

The expanding literature on the social situation of older people has removed all reasonable doubt as to the extent of informal caring by family members. Whether families provide informal care is no longer a question for most researchers and practitioners. Yet how much care, and for how long, continues to be a critical issue for policymakers. Of particular concern is the level of informal care received by older persons who also receive formal services. Clearly, we see government encouragement of family responsibility for care. This current trend is based upon questionable assumptions regarding filial responsibility and containment, if not savings, of public costs for care of an expanding older population. This paper addresses this issue of substitution of formal services for informal care directly by focusing on the relationship between use of formal services and informal care by frail noninstitutionalized older people.

METHOD

A three-stage field design was used to identify and collect data from a community-based, linked random sample of 635 frail elders and 429 of their primary informal caregivers. In Stage I, a geographically stratified random sample was drawn from local census lists. Data collection in this stage consisted of determination of frailty status of the 5,855 individuals generally by mailed administration of the HRCA Vulnerability Index (Morris, Sherwood, and Mor, 1984). Of the 4,774 eligible respondents (87.6% response rate), 18.9% (n=791) were determined to be frail by this HRCA Index and thereby included in Stage II of the study.

Stage II consisted of telephone interviews of the frail elder study sample with in-person interviews when necessary. Data were collected in the following areas: sociodemographics, health status, mobility and functional capabilities (to determine level of impairment), types and sources of assistance with daily living activities, and characteristics of the caregiving network (up to four caregivers). The elder respondents were asked to provide the name, address, and phone number of their primary caregiver, defined as the person who provided them with the most assistance with daily living activities. Both family and friends were included as caregivers to capture more complete informal helping activities.

Stage III involved telephone interviews with these primary caregivers. Data included sociodemographic information regarding both the frail elder and the caregiver, characteristics of the caregiving network (up to three other caregivers), the type, source, amount of formal services utilized by the elder, and physical and mental health status of the caregiver.

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ANALYSIS AND RESULTS

For this random sample of frail elders, informal care was the major source of assistance as indicated by the following findings:

- o 95.6% receive informal care;
- o 80% identified informal caregivers as the major source of assistance;
- o informal caregivers provided the most help in nine of ten areas of care;
- o the average hours/week of informal help was five times the average hours/week of formal services;
- o for 27.3% of elders with informal caregivers, no formal services were utilized at all.

Detailed data regarding the older person's utilization of formal services and informal care were used to analyze the interface of the two systems of care. Types of informal care and formal services were matched where appropriate and utilization rates based on frequency and average duration of contact were developed for each service type. Analysis consisted of:

- o comparison of the amounts (hours per week) of care for each type of help (controlling for level of impairment) to detect significant differences between sources of care;
- o correlation analysis to detect any relationship between sources of care for each type of help; and
- o comparison of the amounts of each type of help according to the living arrangement of the older person.

Key findings are summarized as follows:

- o Informal care predominates over formal services in all areas of assistance.
- o The predominance of informal care persists across all levels of frailty, with substantially larger amount than formal services (60 hours vs. 9.7 hours) at the highest level of impairment.
- o The lack of significant associations between types of informal care and formal service, in conjunction with the actual levels of care, provides no evidence to suggest that formal services replace, or substitute for, informal care.
- o Living arrangement is an important influence on receipt of informal care and utilization of formal services. Older people living with spouse or others receive more informal than formal care in all areas of assistance, whereas those living alone are more likely to use those formal services which are well developed and available.
- o Finally, the vast majority of caregivers report that the type and amount of help which they provide has not changed as a result of formal service utilization.

DISCUSSION

These findings underscore the preponderance of informal sources of care for frail elders. More importantly, the data show that the amount of informal care is substantially higher than the amount of formal care for elders who are severely impaired. Therefore, contrary to assumptions of public policymakers, even when increased needs necessitate more help, informal caregivers are more involved rather than withdrawing assistance in favor of formal services. Even in those areas where one might expect a shift toward formal services because services are well established and readily available (e.g., personal care and housekeeping), the data reveal an increase

in the amount of informal help accompanying an increase in the use of formal services. Even for the most frail elders, formal services remain ancillary to informal care.

The cross-sectional data from this study do not permit the analysis needed to adequately explain the course and changing nature of informal caregiving as an elder's functional status declines. Nor is it possible to definitively explain how and why formal services are utilized as an elder's impairment increases or the capability of the caregiving network to provide help changes over time. Similarly, while a growing body of cross-sectional data casts substantial doubt on the so-called substitution effect of formal services for informal care, limitations of a cross-sectional design of this study and others impede development of a convincing argument.

Longitudinal data on a representative sample of frail elders is necessary to document how care is utilized from informal and/or formal sources at progressive stages of frailty in order to definitively assess any substitution effect. Longitudinal data would permit us to state even more clearly whether informal care is eroded by formal services and to move the development of long-term care policy beyond the argument of the substitution effect.

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